Quality of Life and Person-Centered Care for Older People

Thomas Boggatz
Editor

Springer

Quality of Life and Person-Centered Care for Older People

Thomas Boggatz

Quality of Life and Person-Centered Care for Older People

Springer

Thomas Boggatz
Faculty of Nursing Science
Philosophical-Theological University Vallendar
Vallendar
Germany

ISBN 978-3-030-29989-7 ISBN 978-3-030-29990-3 (eBook)
https://doi.org/10.1007/978-3-030-29990-3

© Springer Nature Switzerland AG 2020
This work is subject to copyright. All rights are reserved by the Publisher, whether the whole or part of the material is concerned, specifically the rights of translation, reprinting, reuse of illustrations, recitation, broadcasting, reproduction on microfilms or in any other physical way, and transmission or information storage and retrieval, electronic adaptation, computer software, or by similar or dissimilar methodology now known or hereafter developed.
The use of general descriptive names, registered names, trademarks, service marks, etc. in this publication does not imply, even in the absence of a specific statement, that such names are exempt from the relevant protective laws and regulations and therefore free for general use.
The publisher, the authors, and the editors are safe to assume that the advice and information in this book are believed to be true and accurate at the date of publication. Neither the publisher nor the authors or the editors give a warranty, express or implied, with respect to the material contained herein or for any errors or omissions that may have been made. The publisher remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

This Springer imprint is published by the registered company Springer Nature Switzerland AG
The registered company address is: Gewerbestrasse 11, 6330 Cham, Switzerland

Contents

1 Old Age and Quality of Life: An Introduction

A Chinese legend tells that the philosopher Laozi at the end of his life left his hometown and rode on a water buffalo to the west. When he reached the border of China he was stopped by a guard who asked him to record his wisdom for the good of the country before he would be permitted to pass. The text that Laozi wrote in response to this request was the Daode jing, which became the foundational scripture of Taoism. When Laozi had accomplished this work, he finally left China and was never seen again. Although modern scholars doubt the historical existence of Laozi (Kohn 2008), the legend nevertheless has a deeper meaning. It conveys an idea of old age and quality of life. Riding to the west is a metaphor for old age and crossing the border of ones homeland refers to the transition from life to death. In this sense, old age is seen as a process of disengagement where an older person gives up his or her social roles and prepares him- or herself for death. It is, however, not a simple retreat during which older persons give up life and learn to accept their losses. It is rather another, even higher form of engagement. Laozi does not simply disappear; he summarizes his life experience and wisdom, leaves a legacy for future generations, and in doing so, he accomplishes his life. The wisdom that Laozi conveys, and that is the final quintessence of his life, consists of the knowledge of the Dao. The Dao is the way that enables human beings to live in harmony with themselves, with the world, and with each other. It is not a set of fixed rules to be followed, but a guiding principle for leading one's own life, which allows finding an inner balance between opposing tendencies in response to given circumstances. It is a sense of the appropriate in every situation that cannot be taught by precise instructions for action. Knowing the Dao is rather an intuition to be awakened by the aphorisms of Daode jing. According to Laozi, the knowledge of the Dao is the key to quality of life and since he needed his whole life to attain it, old age is the period of life where human beings can experience quality of life.

This ancient idea of the connection between old age and quality of life has been echoed by contemporary gerontological theory. Lars Tornstam (2005), a Swedish gerontologist, proposes in his theory of gerotranscendence that older persons in their final stage of life complete the natural process of their development towards

T. Boggatz, *Quality of Life and Person-Centered Care for Older People*,
https://doi.org/10.1007/978-3-030-29990-3_1

maturity and wisdom. They disengage in the sense that they decrease their self-centredness, their desire for material things, their obsession with their body, their longing for prestige and superficial social interactions, and their fear of death. In exchange, they engage on a higher level by increasing their search for inner peace, their tolerance and broadmindedness, their concern for others, their awareness of the mysteries of life, their joy over small things, their appreciation of nature, and their feeling of communion with the universe.

The idea that older persons develop a higher state of wisdom contradicts the prevailing image of old age in our contemporary society. Nowadays, old age is rather associated with a loss of function, physical, and mental decline that finally leads to death. In his essay "On Aging" the Vienna-born essayist Jean Améry describes his own experience of becoming old as living in "a desolate region of life, lacking any reasonable consolation" (Améry 1994, p. 127). And he continues to explain: "As aging people we become alien to our bodies and at the same time closer to their sluggish mass than ever before. When we have passed beyond the prime of life, society forbids us to continue to project ourselves into the future, and culture becomes a burdensome culture that we no longer understand, that instead gives us to understand that, as scrap iron of the mind, we belong to the waste heaps of the epoch" (ibid.). Seen from the perspective of Eastern wisdom, this experience of old age seems to be the fate of people living in a one-sided materialistic society. Sogyal Rinpoche, for example, a teacher of Tibetan Buddhism writes: "Sometimes I think that the most affluent and powerful countries of the developed world are like the realm of Gods described in the Buddhist teachings. The Gods are said to live lives of fabulous luxury, revelling in every conceivable pleasure […]. All seems to go well until death draws near, and unexpected signs of decay appear. Then the god's wives and lovers no longer dare to approach them, but throw flowers to them from a distance […] None of their memories of happiness or comfort can shelter them now from the suffering they face; they only make it more savage. So the dying Gods are left alone to die in misery" (Rinpoche 1992).

According to these authors, it seems to be the paradox of our time that modern society which successfully increased welfare, health, and life expectancy of its members failed to promote what makes life worth living. The above cited authors, however, do not stand alone with this view. It has, in fact, become a common saying that one should not add years to life, but live to years. Old age, which was once perceived to be the fulfilment of human life, has become problematic—so problematic that modern societies made it a topic of scientific investigations. The mere fact that there is a science like gerontology indicates the emergence of this new perspective. Whereas in former times people simply grew old, nowadays there is a need for scientists who investigate this process in order to advise those who experience it. The problem of growing old now needs a remedy and gerontologists proposed several theories to meet this purpose.

On the one hand, there is the disengagement theory (Cumming and Henry 1961). According to this theory, older people should respond to the loss of their social function that accompanies retirement by an acceptance and willingness to disengage. Such acceptance shall increase their well-being and satisfaction with life since they do not struggle in vain to perform roles they are no longer able to perform. On the other hand, there are opponents of this theory who claim that this approach denies older persons the right and the ability to engage with life. Instead of disengaging, older persons shall rather maintain an active way of life in order to overcome the loss of their professional function (Havighurst 1961). They can develop new interests, spend an active leisure time, or take on new responsibilities like volunteering or grandparenting. Such an active way of life will allow them a further participation in their society. It is also believed to be the key to what Rowe and Kahn (1987) termed as successful ageing in contrast to normal ageing, which was susceptible to diseases. In a much cited article, they declared diseases of old age to be preventable if older persons pursued a health-promoting way of life which was based on social and physical activities and a healthy nutrition. Activity theory, however, has been criticized for ignoring the fact that life unavoidably will come to an end and that older persons sooner or later will lose their capabilities. Active ageing may delay the onset of morbidity, but it cannot prevent it completely. To consider active ageing as the only appropriate way of growing old will result in blaming those who are less successful in achieving this goal and suffer from frailty.

There are two things to be learned from this dispute. First of all, there is more than one idea about what constitutes quality of life in old age. All these ideas are furthermore the ideas of experts. They do, however, not necessarily reflect the ideas of older persons themselves. Even more, the underlying assumption seems to be that gerontologists are more knowledgeable about old age and how to deal with it than the older persons themselves. One may, however, raise the question of what growing old means for those who directly experience it. What are their ideas about quality of life? Do they comply with the ideas of the experts who are as scientist still engaged in the working process and do not have any direct experience of being old and retired? Or are not the experts rather running the risk of imposing an idea about quality of life on older persons that they consider to be appropriate? It is a central concern of this book to answer these questions.

The second issue that can be learned from the contemporary dispute about the appropriate way of ageing is that growing old is always related to functional decline and on the long run to care dependency in an either direct or indirect way. Whereas active ageing is concerned about avoiding this situation or at least about decreasing its likelihood, disengagement may foster the abandonment of an active and self-reliant way of life since it considers this to be the normal course of events. One may also ask whether the independent way of growing old as it is depicted in the legend of Laozi provides a realistic picture. We do not know the life situation of older people at his time but it seems unlikely that they were free of age-related disabilities. In fact, during long periods of human history longevity was rather the privilege of a minority. The general increase of life expectancy as it was experienced in the last century by nearly all countries was due to an improvement of the conditions of living worldwide. In the same way, the possibilities to care for frail older persons and to prolong their lives grew considerably.

However, if health professionals begin to take care of older persons they will consciously or unconsciously define quality of life from their own perspective since this is the implicit goal of providing support or care to someone. They are even more likely to impose their idea of quality of life on older persons since they do not offer theoretical guidance but practical support that directly interferes with the older persons' daily life. Since older persons have their own idea about quality of life, well-meant care may impede its realization rather than support it—unless those who provide such care are aware of the perspective of those who receive it. Therefore caregivers and health professionals should pay attention to the person who is the care recipient. They should be person-centred. This idea is inherent in many nursing theories. According to McCormack et al. (2013) "person-centredness is an approach to practice established through the formation and fostering of healthful relationships between all care providers, service users, and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect, and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development" (McCormack et al. 2013, p. 193).

This is of course an ideal and the question remains how it can be implemented in practice. How do health professionals as caregivers and care recipients interact? When do they come to a mutual understanding and when do they fail to do so? When do health professionals promote quality of life of their care recipients and when do they impede it? What are the circumstances of their encounters? It is the aim of this book to understand the meaning of quality of life from the perspective of the older persons and to clarify how health professionals can respond to their idea of quality of life in a person-centred way.

The path to this aim consists of a stepwise approach. Chapter 1 will introduce the reader to the definitions of quality of life as they were developed by scientific experts. As we will see, there is a variety of such definitions, but there is little consensus about the components that shall constitute quality of life. Chapter 2 will change the perspective and explore quality of life as described by self-reliant, community-dwelling older adults. This will offer an idea about the experience of older persons who do not yet have to interact with health professionals and who are therefore not influenced by any kind of health-related intervention. Chapter 3 will introduce the reader to the experience of older persons who are exposed to attempts by health professionals to promote their health and to prevent diseases as it is implied in the idea of active ageing. Such attempts are sometimes in accordance with the perspective of older persons, but can also interfere with or even contradict their ideas. Chapter 4 will explore the experiences of older persons who voluntarily or involuntarily gave up their old place of living and had to move into a long-term setting. They are the ones who are most exposed to the influence of caregivers, nurses, and other health professionals. Chapter 5 will accompany older persons to their last stage of life where they suffer from and have to cope with the process of dying. Chapter 6 finally will look back to these different stages of encounters between older persons and health professionals and answer the question of how health professionals may respond with person-centred care to the needs and the perspective of the older persons.

The way to approach the perspective of older people is to engage with them in a dialogue. In research, this is usually done through qualitative studies. There are, indeed, many qualitative studies that examine the experience and the understanding of quality of life among older persons in different situations of their life. This book attempts to compile these already existing findings in qualitative metasyntheses about each of the abovementioned life situations in order to derive a model of quality of life from the perspective of older persons. Based on this model it tries to outline a way how caregivers, nurses, and other health professionals can approach older persons in a person-centred way in order to promote their quality of life.

References

Améry J (1994) On aging: revolt and resignation. Indiana University Press, Bloomington

Cumming E, Henry WE (1961) Growing old: the process of disengagement. Basic Books, New York

Havighurst RJ (1961) Successful aging. The Gerontologist 1(1):8–13

Kohn L (2008) Laozi and Laojun. In: Pregadio F (ed) The routledge encyclopedia of taoism, vol 1. Routledge, New York, pp 611–616

McCormack B, McCance T, Maben J (2013) Outcome evaluation in the development of person-centred practice. In: McCormack B, Manley K, Titchen A (eds) Practice development in nursing, 2nd edn. Wiley-Blackwell, Oxford, pp 190–211

Rinpoche S (1992) The Tibetan book of living and dying. Rupa, Calcutta

Rowe JW, Kahn RL (1987) Human aging: usual and successful. Science 237(4811):143–149

Tornstam L (2005) Gerotranscendence. A developmental theory of positive aging. Springer, New York

Quality of Life in Old Age: A Theoretical Perspective

2

2.1 Quality of Life: State of the Theory

In view of the increasing number of older adults worldwide quality of life in old age has become an important issue for social, medical, and nursing care. “Add life to years, not years to life” is nowadays a well-established slogan. In this sense, the United Nations’ second international action plan for ageing persons demanded the promotion of active ageing, well-being, and quality of life in old age (Fernandez-Ballesteros et al. 2007). Despite this relevance and despite the widespread use of the concept, its meaning has remained unclear. At a first glance, it refers to something we all believe to be familiar with: a good life. However, if people are asked to specify the meaning of such a good life, there is hardly any agreement that can be reached. In an attempt of clarifying the concept Halvorsrud and Kalfoss (2007) found more than 100 definitions of quality of life and more than 1000 instruments to measure it—either as a whole or in part. In the same way, Walker (2005) asserted in a review about quality of life and ageing in Europe that there is no consensus on definition and measurement. For some authors (Rosenberg 1995) the term encompasses several constructs. Other authors believe that quality of life refers to a single phenomenon that has several dimensions, i.e. physical, cognitive, emotional, and social aspects (Walker 2010; Rokne and Wahl 2011).

A clarification of the concept is important for two reasons: Nurses and caregivers are expected to promote the quality of life of care recipients. They can only do so, if they have a clear understanding of this aim. A concept clarification is needed to inform their practice. Furthermore, care providing institutions need to assess the degree to which they ensure quality of life among residents. Although nursing care is only one among several other factors that impact on quality of life, low quality of life may be indicative of apparent or latent problems that are experienced by residents and that need to be addressed by nurses and caregivers.

Beside its relevance for practice, conceptual clarity is also needed for research. The current lack of an agreed upon definition resulted in studies that aim to determine quality of life without even raising the question of how to define it. Reviews

T. Boggatz, *Quality of Life and Person-Centered Care for Older People*,
https://doi.org/10.1007/978-3-030-29990-3_2

about quality of life ascertained that less than half of the studies purporting to investigate this phenomenon provided a definition of the concept (Halvorsrud and Kalfoss 2007; O'Boyle 1997). As a consequence studies measure different aspects and do not yield comparable results (Low et al. 2008). Furthermore, the same aspect may appear in one study as an influencing factor and in another study as a component of quality of life. With the increasing number of publications about this issue, it has become an increasing problem to distinguish between cause and effect and between aspects of the concept and its related factors (Rokne and Wahl 2011).

In view of the multitude of definitions some authors attempted to clarify the prevailing confusion by developing taxonomies. According to Farquhar (1995) there were global definitions, which refer to life satisfaction or happiness in general, component definitions, which specify subjective or objective aspects of quality of life, focus definitions, which are restricted to just one aspect such as functional capacity, and combined definitions, which include both general satisfaction and individual aspects (Farquhar 1995). This classification differentiates definitions according to formal aspects but is less informative about their content. Brown et al. (2004) suggested a classification according to the content of definitions with the following types: objective indicators, subjective indicators, satisfaction of human needs, psychological models, health and functioning models, social health models, social cohesion and social capital, environmental models, ideographic or individualized hermeneutic approaches. Some of these categories partly overlap (e.g. objective indicators include aspects which also are also part of health models and environmental models and satisfaction of human needs may also be considered as a psychological model), while other categories do not refer to different contents but to different ways of capturing it (e.g. subjective indicators and ideographic approaches). In sum, both approaches are not convincing and informative for practice. A typology of quality of life according to the content of definitions and based on a systematic approach is missing to date.

This chapter will give an overview of this still ongoing discussion. It will explore what experts for gerontological care (nurses, social workers, geriatricians, gerontologists, psychologists, etc.) believe to be quality of life in old age. It will compile their definitions, try to classify them, and discuss their advantages and shortcomings in order to offer a provisional definition of quality of life that may serve as a starting point for the subsequent investigations in this book. This chapter is based on the method of concept analysis according to Walker and Avant (2005) and identifies the current uses of the concept, determines their defining attributes, antecedents, and consequences, and provides model, borderline, and contrary cases for illustrative purposes.

Current uses of the concept were identified by a literature research in the databases MEDLINE, Cumulative Index to Nursing and Allied Health Literature, PsycINFO®, and GeroLit, the database of the German Centre of Gerontology. Papers published in the last 25 years and written in English and German were included. The investigated literature was composed of expert opinions, theoretical work dealing with the concept "quality of life in old age", surveys of quality of life

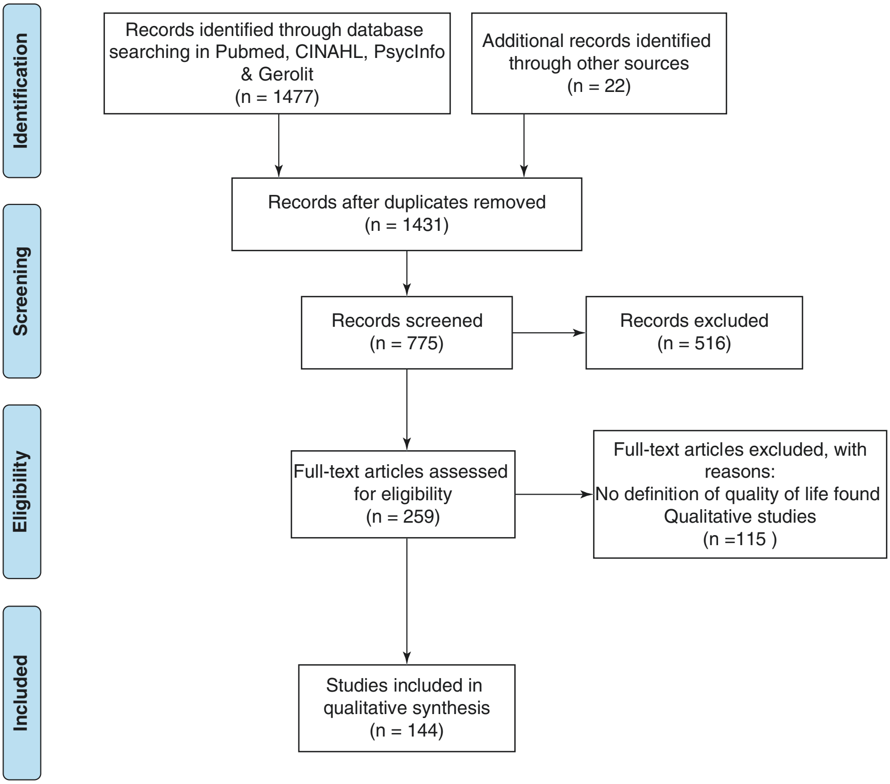

Fig. 2.1 Search strategy according to PRISMA (Moher et al. 2009)

in old age if they provided a definition of this concept, and psychometric studies on instruments to measure quality of life in old age if they provided a theoretical rationale. Figure 2.1 shows the flow diagram of the search strategy with the number of relevant articles according to PRISMA (Moher et al. 2009). Altogether 144 papers were included.

2.2 Quality: A Preliminary Definition

According to Webster's Online Dictionary the term quality has several meanings. It may refer to "an essential and distinguishing attribute of something or someone" or "a characteristic property that defines the apparent individual nature of something". In this broad sense quality of life would encompass all features that characterize the life of a person or a group of persons. The term may furthermore indicate a "degree or grade of excellence or worth". In this sense, quality of life is not simply a neutral description of a person's life but rather a judgement about the desirability of its condition. In literature on quality of life, the phrase is commonly used in this way (Sirgy et al. 2006; Rokne and Wahl 2011). As a value judgement, quality of life may have four different meanings: quality of the objective life situation, general subjective well-being, subjective satisfaction of needs, or a multidimensional subjective state. In the remainder of this chapter these four meanings will be described and discussed regarding their respective advantages and shortcomings.

2.3 Quality of the Objective Life Situation

Quality of life as an objective situation refers to those circumstances of a person's life, which are considered by experts to be relevant for a good life and successful ageing (Smith et al. 2010). Regarding older persons the following components are said to be of particular importance: financial situation; living space including housing conditions, local environment, and transportation facilities; social relationships; health and functional capacities (Tesch-Römer 2002; Walker 2005). A typical case according to this definition would be an older person who had a good position before retirement and receives now a satisfying pension. Living in a safe and clean environment, having family and friends, and enjoying a good health are further aspects that contribute to a high quality of life. A contrary case would be an older person in lack of all these circumstances, and a borderline case would be a person who enjoys only some of these circumstances, while others are missing.

The main antecedent for a particular life situation is a person's biography as each component of this situation is acquired throughout the course of a person's life (Brown et al. 2004). Biography in turn is shaped by age, gender, socio-economic background, and culture. Critical life events such as diseases or loss of a partner impact on the objective situation additionally (Ferring and Boll 2010). The situation is furthermore influenced by all types of support and care that a person does or does not receive. The consequence of the objective situation is a degree of subjective well-being (Brown et al. 2004).

The apparent advantage of this definition is that quality of life can be determined by objectively measurable criteria. One simply has to obtain information about the monthly income, count the number of social contacts, perform a medical check-up, and investigate some environmental criteria like the distance between the place of living and important facilities for daily living. This approach, however, has a serious shortcoming. As quality of life implies a value judgement, someone has to judge how satisfying a certain income, a certain number of social contacts, a particular result of a medical check-up, and so on really is. Of course, 2000 Euro of monthly income are objectively more than just the half of it but the value of a particular sum of money depends on someone who attributes a value to this sum. In this way, for one person 1000 Euro may have the same value as 2000 Euro have it for another person. Hence, information about the objective life situation tells little about how good an observed situation really is with regard to quality of life.

2.4 Quality of Life as General Subjective Well-being

As a consequence of this criticism other authors suggest that quality of life is subjective in nature (Farquhar 1995; Raphael et al. 1995; Rokne and Wahl 2011). The WHOQOL Group summarized this point of view by defining quality of life as the “individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHOQOL Group 1995, p. 1405). In other words, subjective standards provide a criterion to attribute value to the components of objective life situations. These standards may vary from person to person and the same objective situation may be judged in a different way.

The authors who take up this position often equate quality of life with subjective well-being (Spiro and Bosse 2000; Erlemeier 2009; Smith et al. 2010). They describe well-being as a general appraisal of life which has a cognitive and an emotional aspect (Veenhoven 2000). Cognitive appraisal is commonly called life satisfaction and affective appraisal shows itself as positive and negative emotion (Diener 2000; Smith et al. 2010; Ferring and Boll 2010). Hence “a person is said to have high subjective wellbeing if she or he experiences life satisfaction and frequent joy, and only infrequently experiences unpleasant emotions such as sadness and anger” (Diener et al. 1997, p. 25).

Life satisfaction as a cognitive appraisal is based on a comparison of one’s current situation with personal goals and expectations (Brown et al. 2004; Weidekamp-Meicher 2005; Tesch-Römer 2010). Some authors add that life satisfaction has a temporal dimension as it may also refer to past and future expectations (Ferring et al. 1996; Kane 2003; Smith et al. 2010). Satisfaction with the past is the conviction to have made the best out of one’s life, and satisfaction with the future is optimism and positive expectations (Lennings 2000).

Affective appraisal is composed of positive and negative emotions. Empirical studies found that these feelings were not simply the opposite ends of a single dimension but varied independently to one another (Bradburn 1969; Watson and Clark 1999). Bradburn explicates this finding with the example of a man who has an argument with his wife, which may increase his negative feelings without changing his underlying positive feelings.

A typical case of general subjective well-being would be a person who is satisfied with his life, feels happy most of the time, and rarely experiences anger or sadness. A contrary case would be the opposite, whereas a borderline case would be someone who claims to be satisfied by his life but cannot avoid feeling unhappy and sad for some time.

The antecedents and consequences of general subjective well-being can be summarized as shown in Fig. 2.2. The objective life situation is here an antecedent to well-being. It is perceived by the individual (indicated in Fig. 2.2 by the blue circle) and compared to his expectations (indicated by the arrow inside the circle), which depend to some extent on the person’s disposition or habitual way of judgement (Leung et al. 2005; Brown et al. 2004; Diener et al. 1997). If expectations are met the person experiences well-being, whereas unmet expectations (indicated by the

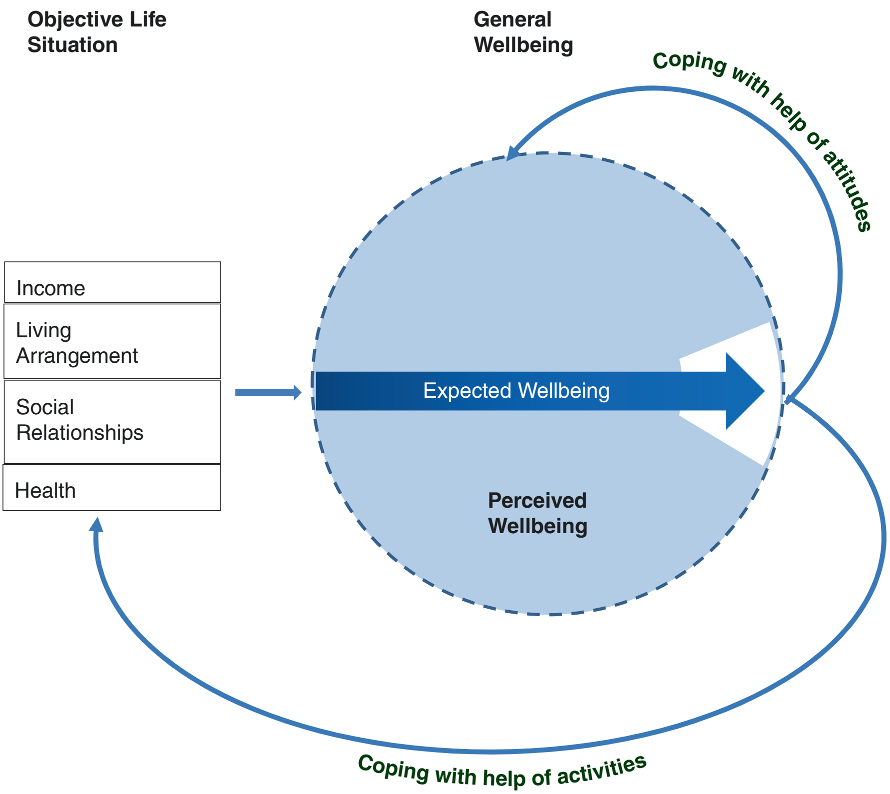

Fig. 2.2 Model of general subjective well-being

white area inside the circle) result in the opposite. This is, however, not a straightforward relationship. Several studies indicate that subjective well-being in old age remains stable despite losses and increasing limitations (Hendry and McVittie 2004; Ferring and Boll 2010). This phenomenon has been labelled satisfaction paradox (Walker 2005). It has been explained by a feedback process where low degrees of well-being produce coping reactions, which impact positively on the antecedents.

There are two basic coping reactions: coping with the help of activities aims at an adjustment of the objective life situation to inner expectations. Older persons try to improve health, social relationships, living arrangements, and income in an active way. They may engage in health promotion, maintain old and search new social relationships, reorganize their space of living, and earn additional money (Ferring and Boll 2010; Ebersberger et al. 2010). In contrast, coping with the help of inner attitudes is the adjustment of expectations to a given life situation (Leung et al. 2005; Erlemeier 2000). Older persons resort to this way of coping when they perceive that their abilities are decreasing. By lowering expectations they may maintain their usual level of well-being (Dietrich 2003; Hendry and McVittie 2004; Smith et al. 2010). A common mechanism of downregulation of expectations is comparison with others (Hendry and McVittie 2004). The awareness that others are worse off increases the satisfaction of older persons with their own situation (Brown et al. 2004; Beaumont and Kenealy 2004).

As quality of life is perceived as a subjective phenomenon the definition circumvents the problem of how to attribute value to an objective life situation. This judgement is left to the individual. A further advantage of the definition is its simplicity. This, however, can also be seen as its major shortcoming because it may oversimplify quality of life. Satisfaction with life in general is a rather all-inclusive judgement that does not reflect the multifaceted aspects of a person's experience. It may also be the reason for the abovementioned satisfaction paradox. Limitations regarding some aspects may be compensated by improvements regarding other aspects so that overall satisfaction remains the same and changes that occurred remain undetected. In any case, general well-being does not disclose what it is composed of.

2.5 Quality of Life as Satisfaction of Subjective Needs

In response to this criticism some authors tried to provide a more detailed picture of subjective quality of life by equating the concept with need satisfaction (Wiggins et al. 2004; Weidekamp-Meicher 2005; Walker 2010). As there are several needs, overall well-being can be conceived as composed of these needs. It is the end sum of their satisfaction. Needs are considered to be universal and shared by all human beings (Higgs et al. 2003). At the same time, universal needs do not preclude individual expectations. The latter are rather individual expressions of underlying universal needs (Higgs et al. 2003; Sirgy et al. 2006). Persons have, for example, different preferences regarding their dishes but they share the same need for food. Needs provide thus a range in which individual expectations may vary and individual expectations are the concrete shape in which universal needs have to be met.

Regarding the question which needs are relevant for older persons gerontologists refer frequently to Maslow's theory (Walker 2005) who distinguishes between physiological, safety, love/belonging, esteem, and self-actualization needs (Maslow 1943). But there are also other suggestions for the classification of needs. Musslewhite and Haddad (2010), for example, propose a model with utilitarian, affective, and aesthetic needs. In terms of social pedagogy Obrecht suggested the categories of biological, biopsychic, and biopsychosocial needs (Ebersberger et al. 2010). To some extent the relevance of needs may be determined by culture (Holzhausen et al. 2009; Erlemeier 2009). Self-realization and self-esteem, for example, may be of higher importance in Western cultures with their emphasis on individualism (Leung et al. 2005), whereas harmonic relationships and fulfilment of family duties may be prioritized in Asian cultures where collectivist values prevail (Diener 2000).

An alternative approach to understand satisfaction of needs does not refer to needs directly but focuses on satisfaction with domains of life that are required to satisfy them (Ferrans and Powers 1992; WHOQOL Group 1995). Relevant domains for older persons are health and functional capacities, finances, living space, availability of public transport, access to medical and social services, relationships to family, neighbours, and friends, social participation, and a positive attitude of society towards older persons (Winkler et al. 2006). These are basically the same domains as in the assessment of the objective life situation with the only difference that they are assessed now subjectively. Whereas the focus on needs captures the extent to which inner goals have been met and may be labelled as "satisfaction of", the focus on domains of life captures the extent to which a person feels that certain circumstances are suitable to achieve such inner goals and can therefore be labelled "satisfaction with". Although both approaches refer at the end to the same feeling of satisfaction, their components have no straightforward relationship. Satisfaction of safety needs, for example, may be related to satisfaction with finances or living space. The other way around, satisfaction with living space may be related to the satisfaction of safety or aesthetic needs.

A typical case of subjective satisfaction of needs would be an older person who eats and sleeps well and can satisfy her mobility needs. She feels safe in her environment, enjoys the company of family members and friends, feels respected by others, has a positive attitude towards herself, and perceives her life as meaningful. In sum, she is satisfied with her life. A contrary case would be a person whose needs have not been satisfied, whereas a borderline case would be someone whose needs are sometimes met and sometimes not.

As with general subjective well-being the objective situation is the antecedent to satisfaction of needs (Fig. 2.3). The variety of needs is symbolized in Fig. 2.3 by the arrows inside the circle. The satisfaction of each need results from a comparison of a current situation with a desired value. If there is no discrepancy between them, the needs of a person have been met (Ebersberger et al. 2010; Diener 2000). The final consequence is general well-being which is the sum of all satisfied needs (represented in Fig. 2.3 by the blue circle) (Diener 2000; Ebersberger et al. 2010; Zeman and Tesch-Römer 2009; Ferring and Boll 2010). A lack of general well-being (indicated by the white area inside the circle) produces feedback that provokes coping with the help of activities or inner attitudes. A reduced satisfaction of one need may furthermore result in an increased importance of another, which is less difficult to satisfy. Decreasing physical capacities, for example, may reduce the satisfaction of the need for mobility (Tesch-Römer 2002) but older persons may start to enjoy small things and obtain inner peace by focusing on religious or spiritual activities, which allow for a reinterpretation of life (Diener 2000). By these coping strategies the sum total of general well-being may remain stable even if particular needs are not satisfied.

In contrast to general well-being the concept of need satisfaction allows for a detailed portrayal of quality of life. The main disadvantage of this concept, however, is the lack of agreement concerning the needs that should be considered as relevant. Experts devised several lists of needs, and the final sum of well-being will vary according to the composition of these lists. At the same time it remains unclear to which extent these lists capture the perspective of the older persons themselves. It is furthermore debatable whether the satisfaction of different needs simply can be added to yield a total.

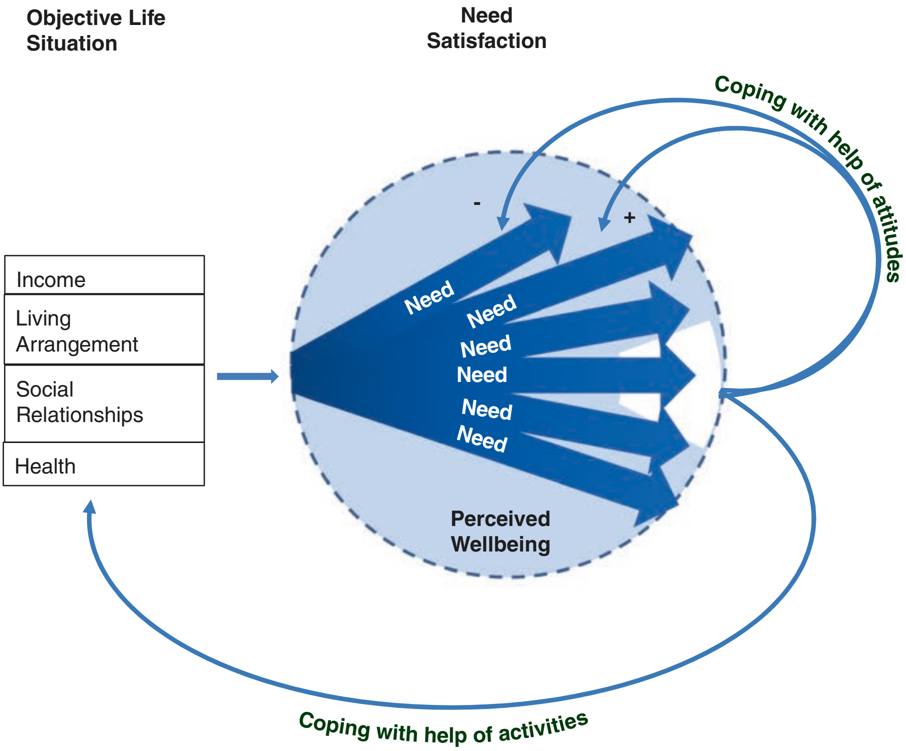

Fig. 2.3 Model of satisfaction of subjective needs

2.6 Quality of Life as a Multidimensional Subjective State

In response to the latter criticism some authors finally perceive quality of life as a multidimensional subjective state. The dimensions of this inner state are actually needs but they are considered to be independent of each other. Hence, if they were added to a total sum the assessment of quality of life would be misleading. Instead, drawing a profile in which each dimension is captured separately seems to be required. Life satisfaction, positive and negative effect are included by some authors in the dimensions of this inner state (Neugarten et al. 1961; Cheung 1997; Higgs et al. 2003), whereas others do exclude them (Ryff and Keyes 1995).

In addition, a variety of further aspects have been suggested as components of the multidimensional subjective state:

- Resolution and fortitude as "the extent to which someone feels responsible for his life" (Neugarten et al. 1961, p. 137).
- Zest, i.e. a certain "enthusiasm of response and degree of ego-involvement" (Neugarten et al. 1961, p. 137).

- Environmental control (Higgs et al. 2003) or environmental mastery (Ryff and Keyes 1995) which is the ability of managing the environment and making use of opportunities according to personal needs.
- Autonomy, i.e. the capability of independent decision-making and the shaping of one's life according to one's own idea and preferences (Ryff and Keyes 1995; Cheung 1997; Higgs et al. 2003).
- Positive social relationships (Ryff and Keyes 1995; Cheung 1997), i.e. being concerned about and having satisfying relationships with others.
- A positive self-perception (Neugarten et al. 1961) or—as Ryff and Keyes (1995) would label it—self-acceptance.
- Purpose in life (Ryff and Keyes 1995; Cheung 1997) which refers to feelings of being useful and having a deeper meaning in life.
- Personal growth (Ryff and Keyes 1995) which means a feeling of continued development and openness to new experiences—an aspect which was labelled self-realization by Higgs and Hyde (Higgs et al. 2003; Hyde et al. 2003).
- Finally, meeting ethical obligations and social duties are said to be important for a good life (Cheung 1997)—at least in collectivist societies where people in contrast to individualistic Western cultures are more likely to sacrifice personal happiness to fulfil their duties (Diener 2000).

A typical case for a high quality of life as a multidimensional subjective state cannot be constructed as the dimensions of this concept do not yield only one total sum. There will be rather different types of high quality of life—some regarding general satisfaction, others regarding social relationship, purpose in life or fulfilment of duties, and so on.

Like in the two previous models, the objective life situation is the antecedent of quality of life as a multidimensional subjective state (Fig. 2.4). However, a comparison between expectations and perceived satisfaction does not result in an overall perception like general well-being. The components of the multidimensional state do not necessarily compensate one another if one of them is less satisfied. Each dimension is an end point in itself and has to be considered separately. Hence, every component has its own way of coping either with the help of activities or with the help of inner attitudes. Some components may be even in conflict with another. Ryff (1989), for example, argues that people may strive for a purpose in life and personal growth while ignoring at the same time that this may at least temporarily reduce their general well-being.

The advantage of defining quality of life as a multidimensional subjective state is that it allows drawing individual profiles of quality of life while avoiding futile discussions about which profile implies a higher level of quality in general. However, like in the previous concept there is no agreement upon the dimensions of quality of life as a multidimensional inner state. It is furthermore debatable that the dimensions of quality of life are completely unrelated. Their interplay remains an open question that needs further investigation.

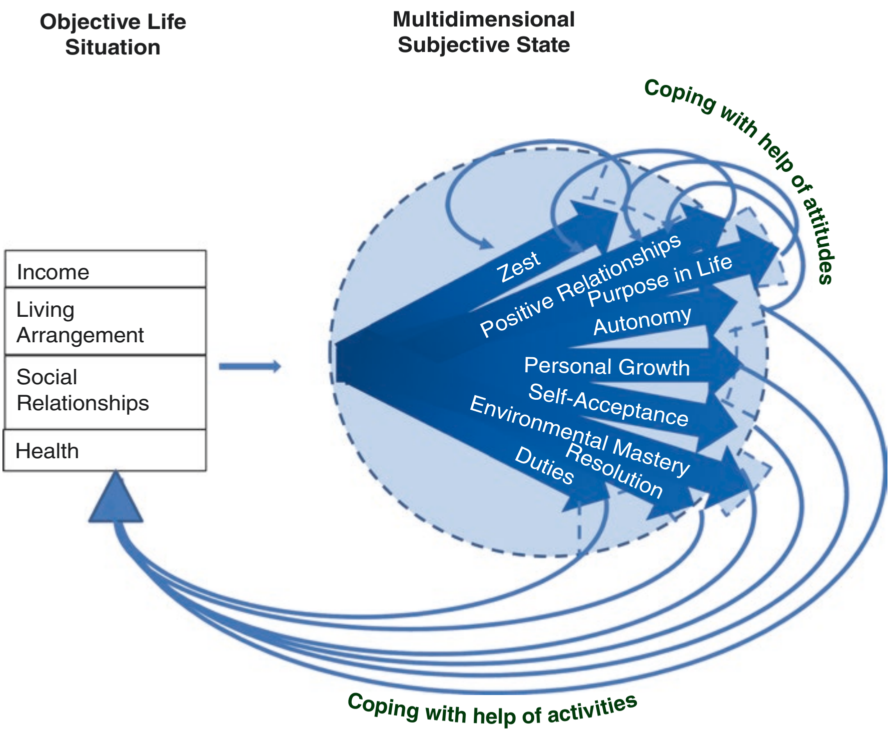

Fig. 2.4 Model of multidimensional subjective state

2.7 Quality of Life: A Person-Centred Approach

To sum up, there are four different definitions of quality of life. However, little agreement exists regarding their components. They provide rather broad categories that allow a classification of the different ways how experts use and understand this concept. Three definitions concur that quality of life is a subjective state which results from objective circumstances and depends on the attitudes and expectations of older adults. However, the particular components of quality of life as suggested by these definitions are based on the assumptions of experts. If the perspective of older person really matters, the best way to determine the components of quality of life will be to ask the people who are concerned. In other words, to determine the meaning of quality of life requires a person-centred approach.

A person-centred approach aims to provide care and support in a way that puts people at the centre of decisions. It is based on the conviction that persons have central concerns according to which they shape their lives. As the German philosopher Heidegger would put it: A person (which he labels in his terminology as *Dasein*) is an “entity for which, in its Being, that Being is an issue” (Heidegger 1962, p. 236). Whatever a person does, it matters to her and has a meaning for herself. That what matters to her are her desires, values, and needs that have evolved in interaction with the social and environmental conditions of her life. It follows that quality of life is experienced when a person achieves what matters to her. Hence, to define quality of life a person-centred approach will start with asking people to tell us what they are concerned about—as it is done in qualitative studies. Instead of determining *the* meaning of quality of life in general, this approach will identify *their* meaning of this concept. The investigation should start with the experiences and needs of community-dwelling older adults. Living independently like most of us, they are able to convey the original perspective of persons who are not affected by the experience of receiving care. Based on a metasynthesis of qualitative research their perspective will be described in the following chapter. The subsequent chapters will explore how the perspective of older persons and their experience of life may change if they receive some kind of care.

References

Beaumont JG, Kenealy PM (2004) Quality of life perceptions and social comparisons in healthy old age. Aging Soc 24(5):755–769

Bradburn NM (1969) The structure of psychological well-being. Aldine, Chicago

Brown J, Bowling A, Flyn T (2004) Models of quality of life: a taxonomy, overview and systematic review of the literature. European Forum on Population Ageing Research. Available at: http://www.ageingresearch.group.shef.ac.uk/pdf/qol_review_complete.pdf. Accessed 08 Nov 2012

Cheung CK (1997) Toward a theoretically based measurement model of the good life. J Genet Psychol 158(2):200–215

Diener E (2000) Subjective well-being. The science of happiness and a proposal for a National Index. Am Psychol 55(1):34–43

Diener E, Suh EM, Oishi S (1997) Recent findings on subjective wellbeing. Indian J Clin Psychol 24(1):25–41

Dietrich H (2003) Lebensqualität im Alter. In: Reuter U (ed) Lebensqualität für alte Menschen in der Pflege. ESI, Bremen, pp 13–31

Ebersberger K, Ebersberger S, Klassen M (2010) Die Theorie menschlicher Bedürfnisse: Entwicklung eines Methodengerüsts anhand einer empirischen Untersuchung zur Lebenszufriedenheit im Alter. Theorie und Praxis der sozialen Arbeit 61(5):388–400

Erlemeier N (2009) Lebensqualität und Wohlbefinden unter erschwerten Bedingungen. Förderung von Ressourcen und Potenzialen im Alter. In: Hölzle C (ed) Ressourcenorientierte Biografiearbeit. Eine Einführung in Theorie und Praxis, 1st edn. Verlag für Sozialwissenschaften, Wiesbaden, pp 236–253

Farquhar M (1995) Definitions of quality of life: a taxonomy. J Adv Nurs 22(3):502–508

Fernandez-Ballesteros R, Kruse A, Zamarrón MD (2007) Quality of life, life satisfaction, and positive aging. In: Ballesteros RF (ed) GeroPsychology. European perspectives for an aging world. Hogrefe, Cambridge, pp 197–223

Ferrans CE, Powers MJ (1992) Psychometric assessment of the quality of life index. Res Nurs Health 15(1):29–38

Ferring D, Boll T (2010) Subjective well-being in older adults: current state and gaps of research. In: Bovenberg AL (ed) Ageing, health and pensions in Europe: an economic and social policy perspective. Palgrave Macmillan, Basingstoke, pp 173–205

Ferring D, Filipp SH, Schmidt K (1996) Die “Skala zur Lebensbewertung”: Empirische Skalenkonstruktion und erste Befunde zu Reliabilität, Stabilität und Validität. Zeitschrift für Differentielle und Diagnostische Psychologie 17(3):141–153

Halvorsrud L, Kalfoss M (2007) The conceptualization and measurement of quality of life in older adults: a review of empirical studies published during 1994-2006. Eur J Ageing 4(4):229–246

Heidegger M (1962) Being and time. HarperCollins, New York

Hendry F, McVittie C (2004) Is quality of life a healthy concept? Measuring and understanding life experiences of older people. Qual Health Res 14(7):961–975

Higgs PFD, Hyde M, Wiggins R, Blane B (2003) Researching quality of life in early old age. Soc Policy Administr 37(3):239–252

Holzhausen M, Bornschlegel U, Fischer T (2009) Die Patientenperspektive in der Erfassung von Lebensqualität im Alter. Z Gerontol Geriatr 42(5):355–359

Hyde M, Wiggins R, Higgs PFD, Blane B (2003) A measure of quality of life in early old age: the theory, development and properties of a needs satisfaction model (CASP-19). Aging Ment Health 7(3):186–194

Kane R (2003) Definition, measurement, and correlates of quality of life in nursing homes: toward a reasonable practice, research, and policy agenda. The Gerontologist 43:28–36

Lennings CJ (2000) Optimism, satisfaction and time perspective in the elderly. Int J Aging Hum Dev 51(3):167–181

Leung BW, Moneta GB, McBride-Chang C (2005) Think positively and feel positively: optimism and life satisfaction in late life. Int J Aging Hum Dev 61(4):335–365

Low G, Molzahn AE, Kalfoss M (2008) Quality of life of older adults in Canada and Norway: examining the Iowa model. West J Nurs Res 30(4):458–476

Maslow A (1943) A theory of human motivation. Psychol Rev 50(4):370–396

Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009) Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. PLoS Med 6(7):e1000097. https://doi.org/10.1371/journal.pmed1000097

Musslewhite C, Haddad H (2010) Mobility, accessibility and quality of later life. Qual Ageing Older Adults 11(1):25–37

Neugarten BL, Havighurst RJ, Tobin SS (1961) The measurement of life satisfaction. J Gerontol 16:134–143

O'Boyle C (1997) Measuring the quality of later life. Philos Trans R Soc Lond B Biol Sci 352:1871–1879

Raphael D, Brown I, Renwick R, Cava M, Weir N, Heathcote K (1995) The quality of life of seniors living in the community: a conceptualization with implications for public health practice. Can J Public Health 86(4):228–233

Rokne B, Wahl AK (2011) Quality of life assessment in health sciences. In: Reuschenbach B, Mahler C (eds) Pflegebezogene Assessmentinstrumente. Huber, Bern, pp 401–416

Rosenberg R (1995) Health-related quality of life between naturalism and hermeneutics. Soc Sci Med 41(10):1411–1415

Ryff CD (1989) Happiness is everything, or is it? Explorations on the meaning of psychological Well-being. J Pers Soc Psychol 57:1069–1081

Ryff CD, Keyes CLM (1995) The structure of psychological well-being revisited. J Pers Soc Psychol 69:719–727

Sirgy MJ, Michalos AC, Ferriss AL, Easterlin RA, Pavot W, Patrick D (2006) The quality of life (QoL) research movement: past, present and future. Soc Indic Res 76(3):343–462

Smith J, Fleeson W, Geiselmann B (2010) Wohlbefinden im hohen Alter: Vorhersagen aufgrund objektiver Lebensbedingungen und subjektiver Bewertung. In: Lindenberger U, Delius J (eds) Die Berliner Altersstudie. Akademie-Verlag, Berlin, pp 521–547

Spiro A, Bosse R (2000) Relations between health-related quality of life and Well-being: the gerontologist's new clothes? Int J Aging Hum Dev 50(4):297–318

Tesch-Römer C (2002) Lebensqualität im hohen Alter: Herausforderungen für Forschung und Praxis. [Quality of Life in Old Age. Challenges for Research and Practice] Blätter der Wohlfahrtspflege 149(5):165–168

Tesch-Römer C, Wiest M, Wurm S (2010) Subjektives Wohlbefinden. [Subjective Wellbeing] In: Altern Im Wandel. Befunde des Deutschen Alterssurveys (DEAS) [Aging in the change. Results of the German Aging Survey] (Motel-Klingenbiel A, Wurm S, Tesch-Römer C eds.) Kohlhammer, Stuttgart, pp. 261–283

Veenhoven R (2000) The four qualities of life: ordering concepts and measures of the good life. J Happiness Stud 1:1–39

Walker A (2005) A European perspective on quality of life in old age. Eur J Aging 2:2–12

Walker A (2010) Ageing and quality of life in Europe. In: Phillipson C, Dannefer D (eds) The SAGE handbook of social gerontology. SAGE, London, pp 573–586

Walker LO, Avant KC (2005) Strategies for theory construction in nursing, 4th edn. Pearson Prentice Hall, Upper Saddle River

Watson D, Clark LA (1999) The PANAS-X: manual for the positive and negative affect schedule - expanded form. University of Iowa, Iowa. Available at: http://ir.uiowa.edu/psychology_pubs/11. Accessed 08 Nov 2012

Weidekamp-Meicher M (2005) Lebensqualität älterer Menschen. In: Schönberg F (ed) Alter hat Zukunft. 15 Jahre gerontologische Forschung in Dortmund. Literatur Verlag, Münster, pp 329–340

WHOQOL Group (1995) The World Health Organization quality of life assessment (WHOQOL): position paper from the World Health Organization. Soc Sci Med 41(10):1403–1409

Wiggins R, Higgs PFD, Hyde M (2004) Quality of life in the third age: key predictors of the CASP-19 measure. Aging Soc 24:693–708

Winkler I, Matschinger H, Angermayer MC, The WHOQOL Group (2006) Der WHOQOL–OLD. Ein Fragebogen zur interkulturellen Erfassung der Lebensqualität im Alter. Psychotherapie, Psychosomatik, Medizinische Psychologie 56:63–69

Zeman P, Tesch-Römer C (2009) Gutes Leben im Alter. Soziale Arbeit 58(11):408–416

Quality of Life: The Perspective of Community-Dwelling Older Adults

3

3.1 Quality of Life in a Person-Centred Approach

In the previous chapter, we discussed theoretical approaches to understand quality of life. These approaches provided a broad framework to understand the concept, but there was no agreement about its dimensions. It seems that attempts to theorize quality of life fail to determine the multifaceted nature of a phenomenon that everybody is familiar with. Quality of life is at the core of our lived experience. Every person feels its presence or absence. Hence, understanding the concept quality of life requires a person-centred approach. An investigation of the lived experience of older persons may help to get a better idea of its meaning. Several qualitative studies have investigated quality of life from the perspective of older adults. To obtain a complete picture of their ideas and concerns one should summarize their findings.

Quality of life or the lack of it can be experienced under different conditions that influence the perspective of older adults. The meaning of the concept may change when they participate in health-promoting activities, when they move to an assisted living or any other long-term care setting, or when they are in the process of dying. As a starting point, we will investigate the perspective of community-dwelling older adults. Since they live independently at home, they will describe the experience of persons in a situation that readers are familiar with. Hence, it will be easy to understand their point of view. Based on a metasynthesis of qualitative research this chapter will explore this perspective. The subsequent chapters will turn to the perspective of older persons who experience one of the other above-mentioned situations.

The studies that are summarized in this chapter were identified by the same literature research as described in the previous chapter. The inclusion criteria, —however, —were restricted to qualitative studies that investigated older person's understanding of quality of life or of one of its related terms, i.e. successful ageing, active ageing, thriving, well-being, and life satisfaction. In order to obtain a realistic picture that addresses also negative aspects of the life of older persons, papers that focused on a particular aspect of their daily life like self-care, social contacts, or spare time activities also were included. The search was restricted to publications

T. Boggatz, *Quality of Life and Person-Centered Care for Older People*,
https://doi.org/10.1007/978-3-030-29990-3_3

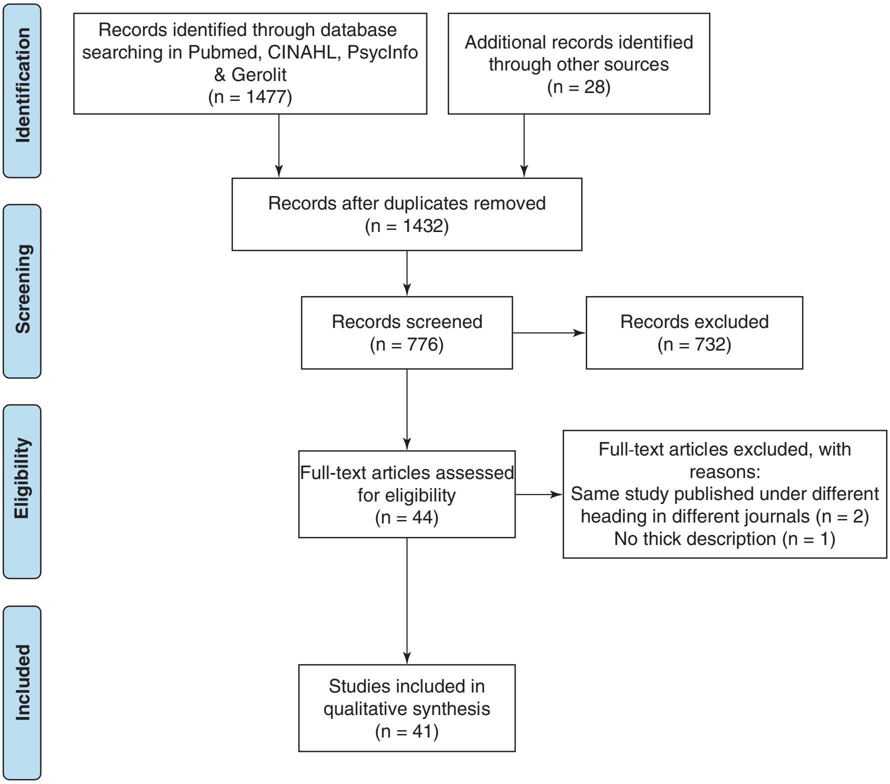

Fig. 3.1 Search strategy according to PRISMA (Moher et al. 2009)

from the last 25 years in English or German. Figure 3.1 shows the flow diagram of the search strategy with the number of relevant studies according to PRISMA (Moher et al. 2009). Altogether 42 papers were identified as relevant and evaluated (Fig. 3.1). In addition, findings from an ongoing study about social contacts and care seeking attitudes of older persons who lived at home or in independent living facilities (Boggatz 2019) supplemented the results.

23 studies have been carried out in Europe (4 in the UK, 10 in Sweden, 1 in the UK and Sweden, 6 in Norway, 1 in Germany, and 1 in the Netherlands), 11 in America (3 in Canada, 8 in the USA), and the remainder in Australia (2), New Zealand (2), Taiwan (1), Hong Kong (1), and finally Nepal (1) the latter providing us with an idea of perspective of older persons in developing countries. Table 3.1 shows the investigated studies sorted by authors and details their places, participants, and methods.

Content analysis according to Mayring (2003) was applied to analyse the identified studies and to synthetize their findings. The method is based on the hermeneutic approach to qualitative research. The process of interpretation starts with the identification of guiding assumptions which have to be refined with each new piece

Table 3.1 Investigated studies by authors and date of publication

Author(s)	Research question	Country	Inclusion criteria	*n*	Data collection by	Research tradition
Andersson et al. (2008)	Aspects of good life in the last phase of life	Sweden	Older persons >75 years	17	Interviews	n.s.
Bauger and Bongaardt (2016)	To identify and describe the general meaning structure of the experience of well-being after retirement	Norway	Older persons >60 years	9	Interviews	Phenomenology
Bergland and Narum (2007)	What means quality of life for elderly women living at home	Norway	Older women >75 years	282	Written responses to open questions	n.s.
Boggatz (2013)	Attitudes of older persons to social contact, volunteering and leisure activities	Germany	Older persons >60 years	31	Interviews	Hermeneutics
Borglin et al. (2005)	What means quality of life for the oldest old	Sweden	Older persons >80 years	11	Interviews	Hermeneutic phenomenology
Bowling et al. (2003)	Older peoples' definitions of, and priorities for a good quality of life	United Kingdom	Older persons >65 years	100	Written responses to open questions	n.s./part of a quantitative survey
Bryant et al. (2004)	What supports quality of life of older persons?	Canada	No age specified	n.s.	Focus groups and interviews	n.s.
Dale et al. (2012)	The meaning of self-care and health for perception of life situation and identity	Norway	Older persons >65 years	40	Interviews	Phenomenology
Dunn and Riley-Doucet (2007)	Themes of holistic well-being vital older adults and self-care activities used to maintain it	USA	Older persons >65 years	28	Focus groups	n.s.

(continued)

Table 3.1 (continued)

Author(s)	Research question	Country	Inclusion criteria	*n*	Data collection by	Research tradition
Farquhar (1995)	Older peoples' definitions of quality of life	United Kingdom	Older persons >65 years	70	Written responses to open questions	n.s./part of a quantitative survey
Fisher (1995)	The meanings older persons attach to life satisfaction and successful ageing	USA	Older persons >60 years	40	Interviews	n.s.
Gabriel and Bowling (2004)	Quality of life from the perspective of older persons	United Kingdom	Older persons >65 years	80	Interviews	n.s./follow-up of a quantitative survey
Green et al. (2005)	How home environment and occupation influences well-being	United kingdom and Sweden	Older persons >80 years	80	Interviews	Grounded theory
Gustafsson and Sidenvall (2002)	Food-related health perceptions and food habits among older women	Sweden	Older women >65 years	18	Interviews	Ethnography
Haak et al. (2007)	What constitutes independence in the home?	Sweden	Older persons >80 years	40	Interviews	Grounded theory
Hambleton et al. (2008)	What means quality of life for older people accessing low-level home support?	New Zealand	Older persons >79 years	9	Interviews	n.s.
Infantino (2004)	To explore and describe the process and content of the lived experience of leisure gardening among older adults in a community setting	USA	Older women >65 years	5	Interviews	Phenomenology
Kalfoss (2010)	Issues of importance to older adults regarding quality of life	Norway	Older persons >60 years	20	Focus groups	n.s.

Knestrick and Lohri-Posey (2005)	To examine health and spirituality in women living in a rural senior high rise	USA	Older women >65 years	10	Interviews	Phenomenology
Kwok and Tsang (2012)	What are the everyday life patterns of active older persons?	Hong Kong	Older persons >60 years	50	Interviews	n.s.
Larson et al. (2009)	What are the everyday doings older persons? How do they manage to live on their own?	Sweden	Older persons >85 years	18	Interviews and observation	Phenomenology
Lette et al. (2017)	Older persons` perspectives on health and living environment in relation to living independently at home, their needs and preferences for receiving care and support	Netherlands	Older persons >55 years[a]	36	Interviews	n.s.
Leung et al. (2004)	What are the components of quality of life for older persons?	Taiwan	Older persons >65 years	44	Focus groups	n.s.
Moore et al. (2006)	What is it that gives a sense of meaning and purpose for living in older adults? What enables older adults to be actively engaged with life?	Canada	Older persons >65 years	11	Interviews	Phenomenology
Musselwhite and Haddad (2010)	The role of mobility and accessibility in older people's self-reported quality of life	United Kingdom	Older persons >65 years	57	Focus groups, interviews and diaries	n.s.
Pettigrew and Roberts (2008)	Methods used by seniors to cope with loneliness	Australia	Older persons >65 years	19	Interviews	n.s.
Reichstadt et al. (2010)	Older adults' individual perspectives on what constitutes successful ageing	USA	Older persons >60 years	22	Interviews	Grounded theory

(continued)

Table 3.1 (continued)

Author(s)	Research question	Country	Inclusion criteria	*n*	Data collection by	Research tradition
Reichstadt et al. (2007)	Opinions of older adults about factors related to successful ageing	USA	Older persons >60 years	72	Focus groups	Grounded theory
Rudman and Durdle (2009)	How older adults with low vision experience and manage community mobility	Canada	Older persons >70 years	34	Interviews	Phenomenology
Shearer and Fleury (2006)	Social support needs and resources for health promotion in community-dwelling older women	USA	Older women >55 years		Focus groups	n.s.
Shrestha and Zarit (2012).	How older women define and assess their quality of life	Nepal	Older women >70 years	6[b]	Interviews	n.s.
Smith (2012)	To explore the meaning of loneliness in community-dwelling older adults and their coping	USA	Older persons >70 years	12	Interviews	Hermeneutic phenomenology
Söderhamn (1998)	To describe self-care ability in a group of Swedish elderly, to elucidate the meaning of actualizing this self-care ability into self-care activity	Sweden	Older persons 67–83 years	22	Focus groups	n.s.
Söderhamn et al. (2011)	To describe the lived experiences of self-care and features that may influence health and self-care among older persons with a strong sense of coherence	Sweden	Older persons 63–73 years	12	Interviews	Phenomenology
Söderhamn et al. (2013)	To investigate the meaning of the actualization of self-care resources[c]	Sweden	Older persons 66–86 years	26	Focus groups	n.s.
Stephens et al. (2015)	What are the aspects of life valued by older people?	New Zealand	Older persons >60 years	145	Interviews	n.s.

Stjernborg (2017)	The meaning of social participation in a neighbourhood for daily mobility in later life	Sweden	Older persons >60 years	40 7	Participant observation Interviews	Ethnography
Sundsli et al. (2013a)	The meaning of self-care and health for the perception of life situation and identity	Norway	Older persons >70 years	9	Interviews	Phenomenology
Sundsli et al. (2013b)	The lived experiences of self-care and features that may influence health and self-care	Norway	Older persons >65 years	10	Interviews	Phenomenology
Wicks (2006)	What are occupational strategies that facilitate successful ageing?	Australia	Older women >65 years	6	Interviews	Hermeneutic phenomenology
Wilhelmson et al. (2005)	What older people consider to be important for their quality of life?	Sweden	Older persons >65 years	141	Written responses to open question	n.s./part of a quantitative survey

n.s. not specified

[a] Study included also health professionals but their perspective is not reported here

[b] Number refers to community-dwelling women, old age home residents were also interviewed but their data are not included in this evaluation

[c] Reanalysis of data from Söderhamn et al. (2011)

of information obtained from the studies. The guiding assumption of this process of interpretation was that older persons have certain tendencies or inclinations to act which can be satisfied to different degrees. It was furthermore assumed that such satisfaction depended on internal conditions and external circumstances, and that older persons will show behavioural or attitudinal reactions in case their inclinations should not be satisfied or if they expect this not to happen. The results of every study were read step by step, relevant statements were extracted and reduced by paraphrasing to core statements. Codes were assigned to statements with similar meanings. Statements could be allocated to different codes, as they could concern several aspects at a time. A category system was constructed by assigning identified codes to categories that either denoted a tendency to act, a physical condition, external circumstances or a behavioural or attitudinal reaction. This category system was refined from study to study until congruence with the complete amount of data was reached. Since it was found that each tendency to act was counterbalanced by an opposite tendency, study results were purposefully searched for statements that could be complemented to pairs of such opposing tendencies. The identified pairs were finally combined in a theoretical model that showed their relationship to each other.

3.2 Quality of Life as Inner Balance

Quality of life according to community-dwelling older adults can be summarized in the following model: Older adults are acting persons. Their actions are not arbitrary; they rather pursue certain interests and follow particular orientations. This does not mean that they try to achieve measurable outcomes. They just act out of their motivation. Imagine, for example, an older woman who likes to meet other people. She goes out to see her friends whenever she is in the mood of doing so. Socializing has become her habit. However, it makes little sense to say that she had a declared goal to meet so and so many people in order to achieve a measurable degree of socializing. She just socialized for the pleasure of doing it.

Underlying such interests and orientations of action are needs. The said woman, for example, has a strong need to socialize. According to Maslow (1943) needs are drives of human behaviour, and human behaviour aims to avoid deficits. Human beings become aware of their needs by feeling the degree of their satisfaction. The satisfaction of a particular need is accompanied by pleasure, whereas its dissatisfaction is accompanied by feelings of unease. When older persons talk about their experiences they rather do not refer to the needs themselves but to the felt degree of their satisfaction. Needs, however, are not simply a power that pushes an individual towards a certain action. Needs are controlled and their satisfaction may be postponed or completely denied. Such control results from the fact that every orientation of action is counterbalanced by its opposite. The need to socialize, for example, is counterbalanced by the need to withdraw in order to have one's privacy. In order to satisfy one's need it is necessary to regard the satisfaction of its opposite. An exaggerated, one-sided satisfaction of only one of a pair of opposite needs would result in the dissatisfaction of its opposite. Exaggerated socializing may result in loss of privacy whereas exaggerated withdrawal may result in loneliness. Opposite needs have to be satisfied in a balanced way. This balance is individual. It depends on the physical and mental capacities of the person, but also on her habits that have evolved in the course of her life. Opposite needs mark the possible range of a person's orientation of action. An individual person, however, will have an inclination to one side of a particular range of needs. For example: Some people are rather loners and withdrawn whereas others are rather sociable types. To a certain extent, inclinations may vary from person to person without creating an imbalance in the satisfaction of their opposing needs. Loners do not necessarily suffer from loneliness; they may achieve social well-being despite their withdrawal by having a small number of social contacts. In the same way, sociable types will not feel harassed by having little privacy. Everybody has his individual style of life and will stick to it as long as his needs and expectations are met. The individual balance between the satisfactions of opposite needs is learned through, and reinforced by experience. Quality of life is achieved by an individually balanced satisfaction of opposite needs. This balance is a product of habit and depends on individual abilities and external circumstances. As a habit, it often remains unreflected. People behave in their individual way because they are used to do so.

There are of course several pairs of opposite needs. Persons do not only develop an individual balance between their desires for closeness and distance. Just to add two more examples: they also try to harmonize their tendency towards independence with their desire to be cared for and their desire for influencing and control on others with their tendency to pay attention to their needs. The combination of individual inclinations within these pairs of orientations of action yields a personality profile. There are, for example, sociable persons with a desire to be cared for who nevertheless refrain from exerting control on their caregivers since they are used to pay attention to the needs of others. But there are also loners who struggle to maintain their independence and strive to exert control on their caregivers in compensation for their lost self-reliance. The pursuit of one orientation of action can at the same time serve to satisfy other orientations of action. The search for social contacts, for example, may also be a way to meet the desire to be cared for and the struggle to remain independent can also mean to establish a desired distance to others. Needless to say, that the satisfaction of one particular orientation of action contributes to the satisfaction of other orientations of action, whereas a dissatisfaction of one such orientation will also have a negative impact on others. For example, receiving care from a family member or a nurse may satisfy the desires for social contact and exerting control on others since it involves getting the attention of the caregiver. A lack of care, on the other hand, can result in a feeling of neglect, loneliness, and loss of control.

The satisfaction of individual orientations of action that make up a person's usual way of life depends on physical and cognitive abilities and on external circumstances. Since these may change, the balance between opposite orientations of actions is fragile and the whole system of these interdependent balances is under threat. A lack of satisfaction of a particular orientation of action is an indicator of a missing balance in the system of opposite needs. To regain the inner balance, older persons have two options: They can increase their efforts to satisfy unsatisfied needs by acting on the environmental conditions or their physical condition that prevented satisfaction. For example: If they cannot meet their desire for closeness and feel lonely due to the loss of old friends, they can try to get into contact with other people in order to find new friends. If they cannot satisfy their desire for physical activity due to a loss of energy they can begin to exercise in order to regain physical strength. On the other hand, they can also try to find a reorientation by changing their inclinations. Older persons may reduce unmet needs and increase others whose satisfaction can compensate for losses. For example: Instead of searching for new contacts they may decide to withdraw into privacy and turn to religious practices to meet their desire for hope. Instead of spending efforts on regaining physical strength they may become inclined to physical rest and develop a desire for being cared for. The way how older persons deal with losses is not determined. Losses are experienced as crises and any response given in order to deal with them does not occur automatically. Every response is the result of a struggle for inner balance which is an open-ended process with no predictable outcome. Older persons may succeed in or fail to regain their inner balance, but to some extent their success will depend on the support they can get from persons in their environment, some of whom are caregivers or nurses.

For the purpose of analytical description pairs of opposite orientations of actions can be divided into four different levels: Body-related orientations of action, social orientations of action, identity-related orientations of action, and developmental orientations of action. In the following, these four levels will be described and explained based on the findings of the qualitative studies. Readers should keep, however, in mind that these levels are not independent from each other in the lived experience of older persons. Rather they are mutually dependent. Through the satisfaction of body-related needs older persons satisfy also social needs and through the satisfaction of social needs they satisfy also identity related and developmental needs. Figure 3.2 shows the integrated system of needs as it could be derived from the qualitative studies. This system will be elaborated throughout the remainder of this book.

Each pair of these orientations of action represents a spectrum of attitudes that could be derived from the statements made by older persons who participated in the qualitative studies investigated here. As their statements showed, orientations of action can be of varying intensity and a particular attitude that was expressed in their statements is similar to a marker point on a scale that reaches from one extreme to the other. Furthermore, orientations of actions are not separate entities with fixed borders. They are rather associated with each other and represent different aspects of the same lived experience that has been divided here into pieces for analytical purposes. This helps to make the inner world of older persons intelligible, but like any other theoretical model it is just an imperfect mean to portray something that has no visible shape.

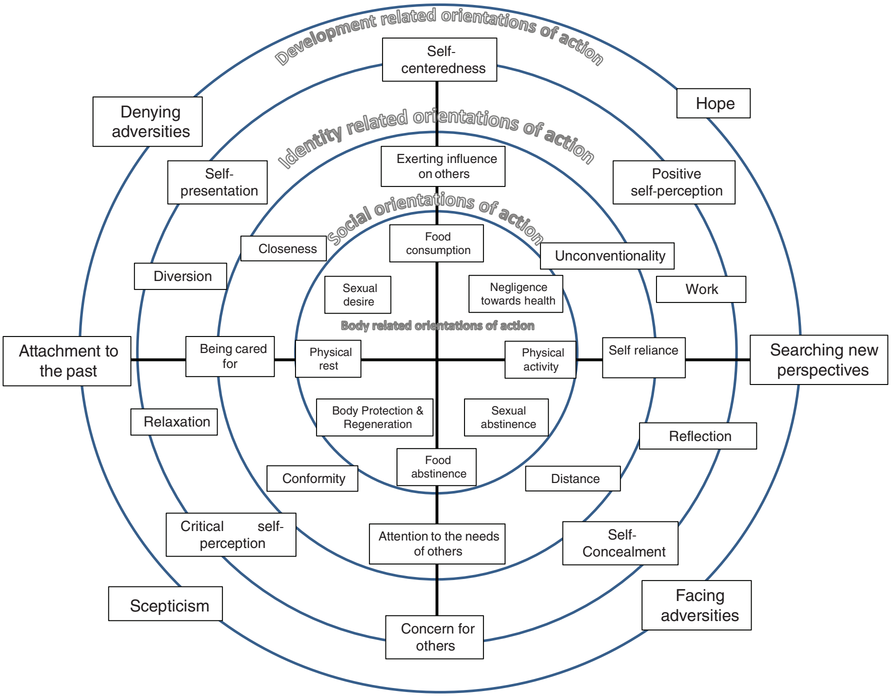

Fig. 3.2 The complete model of orientations of action

3.3 Quality of Life and Body-Related Orientations of Action

There are four opposite pairs of needs inherent in the body-related orientations of action as shown in the inner circle of Fig. 3.3: Physical activity versus physical rest, food consumption versus food abstinence, body protection and regeneration versus laxness, and sexual desire versus sexual abstinence. These orientations are shown in bold letters upon the axes of the cross inside the circle. They have several aspects and result in a certain kind of satisfaction or dissatisfaction. If orientations of action remain unsatisfied older persons may try to cope by showing a behavioural reaction to improve their physical condition and/or to make better use of their external circumstances. They may also try to cope with the help of an attitudinal reaction in order to obtain an inner equilibrium by adapting the underlying needs to the external circumstances and physical conditions.

Table 3.2 provides a summary of these findings. It shows the different aspects of the orientations of actions, the physical conditions and the external circumstances that influence their satisfaction, and the behavioural and attitudinal reactions of the older persons. Aspects listed in the summary table will be explained in the running text where they are shown in italics.

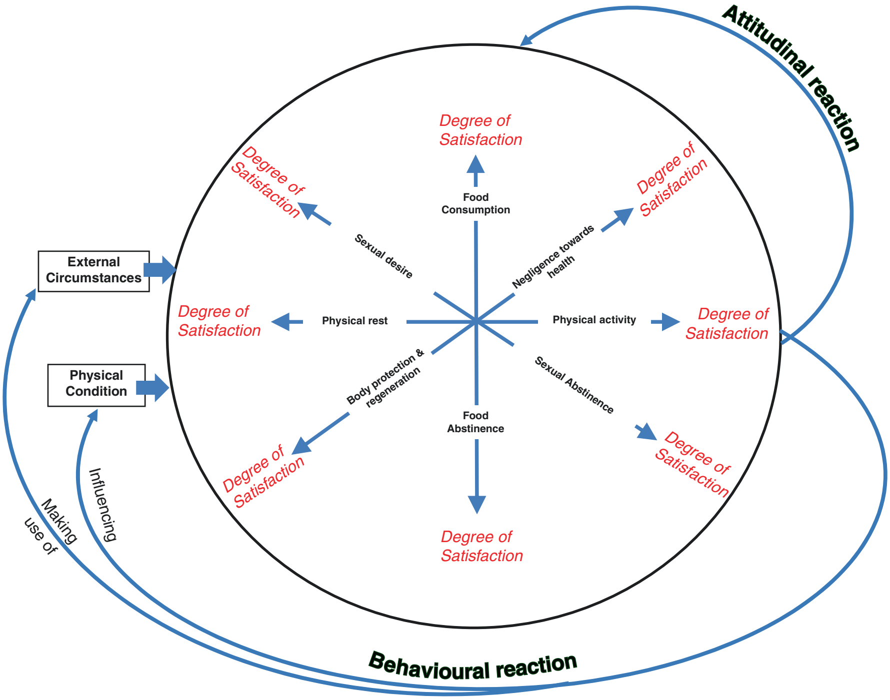

Fig. 3.3 Body-related orientations of action

Table 3.2 Body-related orientations of action, influencing factors, and coping strategies

Orientations of action and their satisfaction	
Physical activity	Desire for physical activity and fitness
Satisfaction of physical activity	Improved fitness
	Joy of being active and alive
	Loss of physical strength
Physical rest	Desire to rest and recover
	Sedentary lifestyle
Satisfaction of physical rest	Physical strain
	Chance to recover
Body protection and regeneration	Concern about physical relief
	General risk awareness
	Fear of injuries/ill-health
	Concern about treatment
	Reduction of pain
Satisfaction of body protection and regeneration	Feeling physically safe
	Health improvements
	Reduced pain
	Injuries
	Ill-heath
	Pain

Table 3.2 (continued)

Negligence towards health	Health care without exaggeration
	Inattentiveness to health
Satisfaction of negligence towards health	Physical comfort with restrictions
Food consumption	Desire to eat well
	Preference of rich and fatty diet
Satisfaction of food consumption	Enjoyment of food
	Having plenty to eat
	Monotonous taste of food
	Disliking the taste of diet
	Feeling hungry
Food abstinence	Preference of a balanced diet
	Reduced intake of calories
	Neglect of food consumption
Satisfaction of food abstinence	Weight loss
	Disgust of fat
Sexual desire	Desire for intimacy
Satisfaction of sexual desire	*(not mentioned)*
Sexual abstinence	Replacing physical intimacy
Satisfaction of sexual abstinence	*(not mentioned)*
Influencing factors	
Physical condition	Limitations of perception
	Functional limitations
	Lack of energy
	Poor health condition
External circumstances	Environmental barriers
	Restricted access to health care
Behavioural and attitudinal reactions	Walking
	Physical exercise
	Use of assistive devices
	Taking a rest
	Diet
	Medical treatment
	Acceptance of physical limitations
	Searching for alternatives
	Denying health problems

3.3.1 Physical Activity Versus Physical Rest

The basic function of the human body is to be in motion. Physical activity is therefore an essential need. Since motion consumes energy, the human body also needs to have some time to rest and to recover. The balance between both orientations of action depends on the physical strength and energy a person has.

3.3.1.1 Physical Activity

One of the most important orientations of action for older adults was their *desire for physical activity and fitness* (Borglin et al. 2005; Moore et al. 2006; Reichstadt et al.

2007; Hambleton et al. 2008; Larson et al. 2009; Söderhamn et al. 2013; Sundsli et al. 2013a). Depending on physical abilities and individual habits, the kind and intensity of physical activity varied, but the underlying need was always similar. As some of the older persons put it:

> And the other thing I do here, weather permitting, I walk a mile every day. … my two good legs, I'm going to keep them moving so I enjoy walking the main thing is to keep the rust down. (Moore et al. 2006)

> I have taken part in sports, not competitive sports, but I have always liked sports. I have skied, I have the gold badge in cross-country skiing which takes six years to get, I have the gold badge in gymnastics, in … well in athletics - I have all the badges that one can get (Larson et al. 2009)

3.3.1.2 Satisfaction of Physical Activity

If older persons could satisfy their need to be physically active, they experienced not only an *improved fitness* (Stjernborg 2017) but also an intrinsic *joy of being active and feeling alive*. As one older woman said: "It keeps me feelin' good" (Dunn and Riley-Doucet 2007), and one older man described a moment from a fishing experience:

> You feel a tug [on the line] - these are fish between 50 and 100 kg - and when you're standing there with your fishing rod […] your heart's beating fast […] that's when you feel alive. (Bauger and Bongaardt 2016)

Others, however, complained about failed attempts to maintain physical fitness and a resulting *loss of physical strength* (Gabriel and Bowling 2004; Borglin et al. 2005; Kalfoss 2010; Shrestha and Zarit 2012).

> Body becomes weak, frail and feeble and cannot walk or work. It is difficult to go up and down the stairs in old age. That is all the difficulties I feel, nothing more. (Shrestha and Zarit 2012)

3.3.1.3 Physical Rest

The orientation towards physical activity was counterbalanced by a *desire to rest and recover* in order to regain strength or in other cases due to a felt lack of strength to perform activities as usual (Leung et al. 2004; Borglin et al. 2005; Reichstadt et al. 2007; Bergland and Narum 2007; Dunn and Riley-Doucet 2007; Larson et al. 2009; Dale et al. 2012):

> Having a sound sleep is good for my health. The elderly should have enough sleep to maintain their health. (Leung et al. 2004)

> Recently there's been a lot of sitting and lying, I simply haven't had the strength there's so much I should do, I should have transplanted the flowers but I can hardly manage to water them (Borglin et al. 2005)

Whereas these quotations indicate that older persons try to achieve a sound balance between activity and rest that is adapted to their physical capacities (Dale et al. 2012), other statements suggest that some of them get used to a rather inactive and *sedentary lifestyle* that is dominated by a desire to rest (Larson et al. 2009). Some older persons attributed this lifestyle change to an age-related loss of energy while others blamed it directly on their own laziness.

3.3.1.4 Satisfaction of Physical Rest

If their desire to rest could not be satisfied older persons felt *physical strain* and exhaustion while performing their daily activities (Borglin et al. 2005; Pettigrew and Roberts 2008), whereas slowing down and rest gave them a *chance to recover* (Leung et al. 2004: Larson et al. 2009).

3.3.2 Body Protection and Regeneration Versus Negligence Towards Health

Physical activity is associated with a risk of injury. Older people can experience falls that cause fractures and other tissue damages. With increasing age there are also further health risks. It is therefore not surprising that older people sought to protect their physical integrity and tried to restore it if they were harmed by disease. An exaggerated desire for body protection may, however, restrict their normal way of life. For this reason, body protection had to be counterbalanced by some negligence towards health.

3.3.2.1 Body Protection and Regeneration

Performance of physical activities and search for rest were influenced by the orientation towards body protection and regeneration. Some older persons reported how they were *concerned about physical relief* on a very basic level:

> When I am not able to find a comfortable position in my bed, I get up and adjust this armchair into a comfortable position, and I may sleep here for several hours (Dale et al. 2012)

Beside such actions to eliminate direct discomfort older persons showed a *general risk awareness* regarding their physical integrity and health. They saw others in their cohort, either in their own personal network or through the media, who had some loss of functioning due to a frail body. For this reason, they went to medical check-ups and observed preventive measures prescribed by their general practitioner (Söderhamn 1998; Söderhamn et al. 2011; Bauger and Bongaardt 2016). The desire to protect the body was most explicit in the *fear of injuries and ill-health*, and older persons were concerned about precautions to avoid harm (Bowling et al. 2003; Gabriel and Bowling 2004; Leung et al. 2004; Rudman and Durdle 2009; Larson et al. 2009; Hambleton et al. 2008; Dale et al. 2012).

> My health means everything to me! They say to me that I am lucky to be in such a good health. But then I use to say that I do a lot of things for it myself (Dale et al. 2012)

> I don’t go down to the barn. I’m afraid to go down to the barn anymore because if I trip on something and fall. I won’t go out around the yard unless I’m quite safe. (Rudman and Durdle 2009)

If they already suffered from a disease they were *concerned about its treatment* and the *reduction of their pain*. This triggered an adherence to medical therapy and—if possible—to physical activities if they were perceived to be beneficial (Leung et al. 2004; Dunn and Riley-Doucet 2007; Hambleton et al. 2008; Dale et al. 2012; Bauger and Bongaardt 2016).

> I have a lot of back pain. But then, the best medicine for me is to take a walk in the wood or to do some outside homework. I have experienced this to be a nice and effective way to get rid of the pain. (Dale et al. 2012)

3.3.2.2 Satisfaction of Body Protection and Regeneration

Caring for the protection of their body, e.g. by using a walker to prevent falls, made older persons *feel physically safe* (Green et al. 2005), and a comfortable home also contributed to this effect (Stephens et al. 2015). Exercises, diets, and attentiveness to medical treatment could result in *health improvements* and *reduced pain* (Leung et al. 2004; Hambleton et al. 2008; Dale et al. 2012). Quite often, however, the desire for body protection could not be satisfied and older persons had *injuries* and experienced *ill-health* and *pain* (Bowling et al. 2003; Gabriel and Bowling 2004; Larson et al. 2009; Sundsli et al. 2013b).

3.3.2.3 Negligence Towards Health

Despite the prospect of such negative outcomes, there were older persons who tended to be easy-going. They perceived preventive measures and medical check-ups to be rather bothersome and wanted to *care about their health without exaggeration* (Leung et al. 2004; Borglin et al. 2005; Hambleton et al. 2008).

> As long as you're healthy there's no problem, a few aches and pains you always have, but that's nothing to make any fuss about (Borglin et al. 2005)

> Being easy-going is good for the elderly… do not take things so seriously. (Leung et al. 2004)

Some even admitted their *inattentiveness to health* and just took their health for granted (Dunn and Riley-Doucet 2007). This attitude represents the opposite to the concern for body protection and regeneration and was apparently supported by good health that allowed for some carelessness.

3.3.2.4 Satisfaction of Negligence Towards Health

Such negligence was motivated by a feeling, that life was more pleasurable without permanent worries about health. Inattentiveness to one's physical condition allowed for *physical comfort without restrictions*—at least as long as there was no serious disease. As one of them put it: "You'd be wasting your time having a good life" (Hambleton et al. 2008). In contrast, exaggerated concern about body protection resulted in a feeling of undue restrictions that rather prevented physical well-being than promoting it.

3.3.3 Food Consumption Versus Food Abstinence

Physical activity requires a supply of energy by the consumption of food. Older persons, however, may have a lower need for energy since their physical activity is reduced. In order to avoid overeating, they tend to abstain from too much food.

3.3.3.1 Food Consumption

For many older persons consumption of food was not only a necessity but also a source of pleasure. They had a *desire to eat well* and it meant for them to feel healthy.

> Well I believe in eating, I mean we don't eat elaborately, don't get me wrong, we don't eat expensive foods, but what we do eat I make sure that we eat well. (Stephens et al. 2015)

Some older person even *preferred a rich and even fatty diet*. They used butter for frying and cream in gravy since these gave a better taste (Gustafsson and Sidenvall 2002).

3.3.3.2 Satisfaction of Food Consumption

Several older persons described their satisfaction of food consumption as an *enjoyment of food* (Gustafsson and Sidenvall 2002). For others, satisfaction of food consumption simply meant *to have plenty to eat* so that they did not have to worry about hunger (Fisher 1995). Their emphasis on the quantity of food is likely to be a result from hard times they experienced like the Great Depression when the availability of food could not be taken for granted. Similar experiences are likely to shape the satisfaction of older persons in developing countries like Nepal (Shrestha and Zarit 2012) where prosperity is restricted to a minority of the population. There were, however, also older people in more affluent countries who lived in constrained circumstances and had to cut down their spending on food. Although they did not go hungry they complained about *the monotonous taste of their food.*

> I eat sandwiches every day. I get fed up. (Stephens et al. 2015)

When older persons with a desire for rich and tasty food tried to observe recommendations for a healthier nutrition, they *disliked the taste of the diet* (Gustafsson and Sidenvall 2002). A limited intake of calories during the day made them *feel hungry* in the evening and they consoled themselves by eating (Gustafsson and Sidenvall 2002).

3.3.3.3 Food Abstinence

Food consumption was counterbalanced by a tendency to food abstinence. Some older persons expressed a *preference for balanced diet* that was composed of fruits, vegetables, and fish (Söderhamn et al. 2011). Although the precise components of such a diet are likely to depend on regional cultures and individual habits, the underlying idea was that a low-fat diet and a *reduced intake of calories* would be beneficial to health as it reduced levels of blood glucose and cholesterol and helped to keep weight down (Söderhamn et al. 2011, 2013). Being aware of this issue some older women reported a sense of guilt when they used cream and butter for cooking (Gustafsson and Sidenvall 2002). Such abstinence was partly due to health messages in the media, partly due to an increasing concern about one's health with growing age. As some older women put it:

> Now I have to pay attention to the foods I eat.
>
> As I began to grow old, I began to realize that I had to know what is right and wrong (Dunn and Riley-Doucet 2007)

Whereas these older persons tried to maintain a healthy balance between food consumption and abstinence, others showed a one-sided tendency to *neglect food consumption*. These were widows who had been used to cooking for their husbands, but now that they lived alone, cooking had lost its meaning. Eating was perceived as a mere duty and was reduced to the intake of fuel:

> I used to think it was fun to cook but now I do it only because you're supposed to (Borglin et al. 2005)

> I don't always eat because I'm hungry…I do eat, I try anyway… (Gustafsson and Sidenvall 2002)

3.3.3.4 Satisfaction of Food Abstinence

For those who voluntarily restricted their diet an apparent benefit of food abstinence was *weight loss* (Söderhamn 1998). Beside this long-term effect, some older persons also expressed a *disgust of fat* if they were forced to eat it. They reported memories from childhood, when they had to eat meals with wobbling fat since it was considered to be good food in a time when people had to work hard and had limited resources (Gustafsson and Sidenvall 2002).

3.3.4 Sexual Desire Versus Sexual Abstinence

The final pair of opposite needs on the level of body-related orientations concerns older persons' sexuality. Only one study, however, addressed this issue (Kalfoss 2010). Older persons' are not likely to mention this aspect when they talk about their quality of life— partly because sexuality is not a topic in a formal conversation, partly because sexuality is considered to be a taboo for older persons. Tarzia et al. (2013) reported reluctance of residents in long-term facilities to discuss this issue and it may be that researchers avoid questions concerning sexuality in anticipation of such reactions. This, however, does not mean that older persons are not interested in sexuality. They may have a strong tendency to sexual abstinence, but at least some of them still have sexual desires.

3.3.4.1 Sexual Desire

Kalfoss (2010) provides us with some of the rare evidence for this claim. Some of her participants talked about their *desire for intimacy* and their ways to find sexual pleasure even with restricted sexual functions.

> One doesn't have to have sexual intercourse to be sexual. There is a lot you can do together, use your skin, your body, caress and give each other orgasms. (Kalfoss 2010)

3.3.4.2 Sexual Abstinence

Others, however, were less concerned about sexual pleasure and tended to be abstinent by *replacing physical intimacy* with other aspects of their partnership.

> Our anatomy makes sure that there is little left, therefore, you need to substitute sex with other qualities in life. (Kalfoss 2010)

3.3.5 Influencing Factors

The satisfaction of the body-related orientations of action depended of course on the older persons' physical condition and the external circumstances in their environment.

3.3.5.1 Physical Condition

Limitations of perceptions, mainly impairments of hearing or vision, prevented older persons from being physically active as they desired (Smith 2012). *Functional limitations* and *lack of energy* had the same effect (Bowling et al. 2003; Gabriel and Bowling 2004; Wilhelmson et al. 2005; Kalfoss 2010; Shrestha and Zarit 2012; Sundsli et al. 2013b). Older persons attributed these limitations to their *poor health condition* (Gabriel and Bowling 2004; Larson et al. 2009; Sundsli et al. 2013b; Stephens et al. 2015).

3.3.5.2 External Circumstances

In addition to these bodily restrictions older persons also perceived *environmental barriers* for satisfying their body-related orientations of action. Walking and outdoor exercise was impeded by poorly kept pavements and streets with fast traffic that made older persons with visual impairments or functional limitations feel insecure (Musselwhite and Haddad 2010). Lack of public conveniences and lack of benches prevented older persons from getting rest during the performance of physical activity (Musselwhite and Haddad 2010). *Restricted access to health care* was another issue mentioned by some older persons.

> So then you get cuts in services…lying on gurneys in hospital hallways and having to wait for surgery and not getting adequate care because there are not enough backup staff, nurses, and technicians...staff are overworked and can't give tender loving care. (Bryant et al. 2004)

3.3.6 Behavioural and Attitudinal Reactions

If older persons were unable to satisfy their body-related orientations of action or perceived their satisfaction to be threatened they showed behavioural and attitudinal reactions. They either tried to continue the pursuit of their usual inclinations or they began to change them. Being aware of decreasing health and fitness, they made attempts to influence their physical condition positively in a variety of ways. *Walking* and *physical exercise* was used to maintain or improve physical strength (Bowling et al. 2003; Green et al. 2005; Reichstadt et al. 2007; Dunn and Riley-Doucet 2007; Hambleton et al. 2008; Larson et al. 2009; Musselwhite and Haddad 2010; Kwok and Tsang 2012; Sundsli et al. 2013a) and sometimes to alleviate existing pain (Dale et al. 2012). The *use of assistive devices* like walkers served the same purpose while protecting the body from injuries at the same time (Green et al. 2005; Dunn and Riley-Doucet 2007; Larson et al. 2009; Söderhamn et al. 2011; Dale et al. 2012; Sundsli et al. 2013a). *Taking a rest* allowed them to recover (Reichstadt et al. 2007; Dunn and Riley-Doucet 2007) and some observed *diets* in order to reduce unnecessary weight that impeded their mobility (Reichstadt et al. 2007; Dunn and Riley-Doucet 2007). Finally, *medical treatment* and adherence to prescribed therapy helped to improve the older persons' health condition (Leung et al. 2004; Reichstadt et al. 2007; Dunn and Riley-Doucet 2007; Hambleton et al. 2008; Dale et al. 2012; Sundsli et al. 2013a).

If attempts to improve their fitness seemed to fail, older persons began to change their inner attitudes. They *accepted their physical limitations*, gave up activities deemed to be strenuous or risky, and slowed down activities they still wanted to perform (Fisher 1995; Gabriel and Bowling 2004; Infantino 2004; Borglin et al. 2005; Bergland and Narum 2007; Dunn and Riley-Doucet 2007; Larson et al. 2009; Rudman and Durdle 2009; Kalfoss 2010; Musselwhite and Haddad 2010; Reichstadt et al. 2010; Dale et al. 2012; Sundsli et al. 2013a).

> Well, you have to know your limits because, when you feel that it's more than you can manage, you have to take a rest and then you can do it again after a while, you have to accept that and live with it, you know about it, you feel when you're going too far, you have to move so that the body will function but I can't over-exert myself more, you have to balance between the two. (Borglin et al. 2005)

> You have to leave yourself plenty of time. Everything is longwinded and slow. (Larson et al. 2009)

Not surprisingly, these older persons *searched for alternatives* like public transport in order to stay mobile (Musselwhite and Haddad 2010). In this way they tried to find a new balance between their opposite body-related orientations of action.

> See I used to go maybe up to … M. [a shopping center]. I used to go up there occasionally but I wouldn't dream of going there now… . I can't walk that far and I have to do a lot of stopping and those malls are tiring (Rudman and Durdle 2009)

Other older persons, however, had a tendency to ineffective coping strategies. Instead of caring for their health they tended *to deny health problems*. Fear of being confronted with a negative diagnosis prevented them from going to the doctor.

> When I get sick, I hesitate to visit doctor. I'm a little bit pessimistic… I just cannot look at things in a positive way… (Leung et al. 2004)

3.4 Quality of Life and Social Orientations of Action

Persons are not just concerned about their body. Persons are social entities and exist in relationships with others. Physical well-being and fitness are preconditions for establishing social relationships, and social relationships give a further meaning to body-related orientations of action. People want to be mobile in order to socialize with relatives and friends, consumption of food is not simply an intake of calories but also a social event, staying active does not only promote physical fitness, it also allows remaining independent from the help of others, protecting the body does not simply mean to prevent or treat diseases, it also implies an adjustment to social norms, and sexuality is not only physical pleasure but an integral part of a close relationship.

In order to establish and maintain social relationships older persons have to find a balance between opposite orientations of action. These are: the desire for being cared for versus the desire for self-reliance, the tendency to exert influence on others versus the tendency to pay attention to their needs, the inclination to social adjustment versus the desire for unconventionality, and the need for closeness versus the need for distance. Figure 3.4 shows these orientations of action in their interplay with physical conditions, external circumstances, and behavioural and attitudinal responses. Table 3.3 provides a detailed list of the aspects of these categories. Again, these aspects will be explained in the running text where they are shown in italics.

3.4.1 Self-Reliance Versus Being Cared for

Human beings are unable to survive without the help and the support from others. Even Robinson Crusoe had such support when he stranded on a lonely island because he still had some tools from the shipwreck that had been produced by other people. The vulnerability of human nature implies a desire for being cared for. People search for the help and support of others to feel safe and protected. At the same time, however, such reliance on others entails a loss of abilities that restricts one's independence. For this reason, the desire to be cared for is counterbalanced by a need for self-reliance. Self-reliance has to be understood as a way of establishing a relationship with others, since independence means always to be independent from others and the pursuit for independence is thus a way of relating to them.

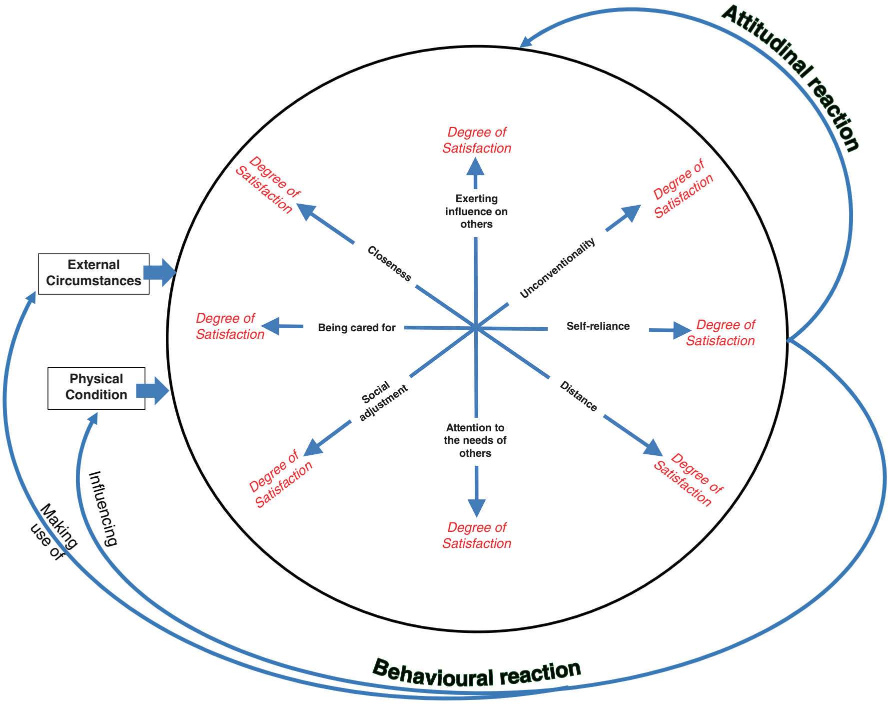

Fig. 3.4 Social orientations of action

Table 3.3 Social orientations of action, influencing factors, and coping strategies

Orientations of action and their satisfaction	
Self-reliance	Retaining abilities
	Fear to loose self-care abilities
	Taking the initiative
	Taking responsibility for one's health
Satisfaction of self-reliance	Feeling of independence
	Loss of self-care abilities
Being cared for	Desire for supportive information
	Searching for occasional help
	Desire to be cared for by the family/spouse
	Getting care when needed
Satisfaction of being cared for	Feeling supported by others
	Possibility of getting help when needed
	Feeling sheltered at home
	Insecurity through information
	Feeling exposed to threats
Exerting influence	Staying in control if receiving help
	Demanding respect from family
	Low tolerance

Table 3.3 (continued)

Satisfaction of exerting influence	Maintaining self -determination while receiving care
	Restricted self-determination when receiving care
	Restricted control under medical treatment
	Being dependent on public transport
	Restricted control due to lack of money
	Restricted self-determination due to spouse
	Regained self-determination after death of spouse
Attention to the needs of others	Fear to become a burden
	Increased tolerance
Satisfaction of attention to the needs of others	Being a real burden
Social adjustment	Observing social norms
Satisfaction of social adjustment	Feeling to do the right thing
	Feeling guilty when breaking a diet
Unconventionality	To do what one likes to do
Satisfaction of unconventionality	Enjoying life without undue restraint
Closeness	Desire for social participation
	Search for contacts
	Group membership
	Maintaining individual contacts
	Attachment to family/spouse
	Finding a new partner
Satisfaction of closeness	Happiness with spouse
	Romantic relationships
	Attention from family/from friends
	Gain of contacts
	Chance encounters
	Attention from substitutes
	Feeling excluded from participation
	Trying to avoid feelings of loneliness by distraction
	Lack of suitable contacts
	Loneliness
	Grieving for the loss of a partner
Distance	Need for temporary distance
	Preferring to be alone
	Dislike of groups
	Limited contact needs
	Rejecting contacts at all
Satisfaction of distance	Enjoyment of privacy
	Intrusion into privacy

(continued)

Table 3.3 (continued)

Influencing factors	
Physical condition	*(same as under body-related orientations of action)*
External circumstances	Housing condition
	Safe environment
	Social climate
	Access to information Access to contact opportunities
	Transportation facilities
	Sufficient income
	Access to assistance
	Support from children
Behavioural and attitudinal reactions	Going out
	Maintaining contacts
	Joining gatherings
	Grand parenting
	Volunteering
	Using communicative devices
	Dealing with pets
	Watching television
	Social withdrawal
	Escapism
	Calming oneself down
	Intimacy without sexuality
	Accepting life as it was
	Resilience
	Denial of care dependency

3.4.1.1 Self-Reliance

Retaining abilities was a major concern for older persons. To avoid dependency on the help of others they wanted to be self-reliant and manage their daily life on their own, even if they encountered difficulties in doing so (Fisher 1995; Bowling et al. 2003; Gabriel and Bowling 2004; Leung et al. 2004; Knestrick and Lohri-Posey 2005; Haak et al. 2007; Bergland and Narum 2007; Dale et al. 2012; Stephens et al. 2015; Lette et al. 2017)

> The most important thing about home is that I am independent, which means that I must force myself to manage. Even if it is hard I have to do it. And if I couldn't manage it would be a mess, and I would not be able to live. (Haak et al. 2007)

> I prepare my own food. Although I use twenty minutes to make coffee and pour it into the coffee pot, and thereafter place myself in a good chair, it is a great satisfaction for me to manage it on my own. (Dale et al. 2012)

Thinking about the future, these older persons were aware that they might become frail and they *feared to lose their self-care abilities* (Gabriel and Bowling 2004;

Hambleton et al. 2008; Larson et al. 2009). Being helpless would make them dependent on the help of others. This was perceived as a serious threat to their ability to exert control which will be discussed in the following section.

In order to avoid or at least to delay such an undesirable future some older persons were aware that they had to *take the initiative* (Kalfoss 2010: Sundsli et al. 2013a).

> You have to take the initiative yourself and keep going. (Kalfoss 2010)

This also meant that they took the *responsibility for their health*, gave up unhealthy habits like the consumption of alcohol and tried to maintain a healthy lifestyle (Söderhamn 1998; Green et al. 2005; Wicks 2006; Knestrick and Lohri-Posey 2005; Söderhamn et al. 2013; Lette et al. 2017). In this way, risk awareness and fear of ill-health became a matter of their desire to remain independent and self-reliant.

> I think it's everybody's duty to look after their own body, you see. I feel this very strongly… It's up to us all to live a healthy lifestyle (Green et al. 2005)

> No, that's your own responsibility. You'd need to pull yourself up by the bootstraps. (Lette et al. 2017)

3.4.1.2 Satisfaction of Self-Reliance

A *feeling of independence* was the direct result of efforts to remain self-reliant (Hambleton et al. 2008; Larson et al. 2009). The own home was the place where older persons could experience such self-reliance (Borglin et al. 2005; Green et al. 2005; Stephens et al. 2015)

> The most important thing with home is that I am independent (Green et al. 2005)

Having a car also contributed to the feeling of independence (Bowling et al. 2003; Musselwhite and Haddad 2010). Some older persons welcomed assistive devices as these allowed remaining self-reliant when suffering from functional limitations (Gabriel and Bowling 2004; Green et al. 2005; Haak et al. 2007; Sundsli et al. 2013a):

> I should buy myself one of those adjustable beds. And a chair that I could stand up (from) easily … and I should have some cupboards, in my bedrooms … that would make life easier. … I could be independent until … the rest of my days. (Gabriel and Bowling 2004)

On the other side, a *loss of self-care abilities* had a negative impact on the older persons' well-being. It restricted their freedom to move around and behave according to their own desire and made them dependent on the help of others which implied the risk of losing control over one's life (as described in the following section). Accidents could result in the experience of needing at least temporarily personal care.

> I fell in the street. I fell here, and got my bone fractured here. Oh my god! I had to eat by this left hand. I had that difficulty. I had to become dependent on others. I had to be dependent that who will cook and feed me. Dependent life is painful, isn't it? That made my life really very difficult. (Shrestha and Zarit 2012)

3.4.1.3 Being Cared for

There was, however, no absolute desire for self-reliance. Due to the vulnerability inherent in the human nature support from others was welcome to some degree. Older persons had a need for care and security. When receiving medical treatment, for example, they had a *desire for supportive information* as it helped them to manage their disease.

> I guess it applies to all patients, but primarily to an older patient, who needs the assurance… sit with the patient and say this is what the doctor has found out and this is what the program is going to be and this is how we're going to handle it and so forth. (Reichstadt et al. 2010)

Older persons also *searched for occasional help* from neighbours or friends as it provided a sense of security (Gabriel and Bowling 2004; Bergland and Narum 2007; Rudman and Durdle 2009; Dale et al. 2012). Moving into a retirement community as they exist in the USA fulfilled the same purpose (Reichstadt et al. 2007). There was also a *desire to be cared for by the family* or—if still existent—by the spouse (Leung et al. 2004; Bergland and Narum 2007; Reichstadt et al. 2007; Hambleton et al. 2008; Shrestha and Zarit 2012). Such support was perceived as a necessary supplement to independence:

> You really think that you have accomplished it on your own when you become successful and made a lot of money and all that. But, if you stop and think about it, you did have help along the way.
>
> You need some significant person that you can depend on, that they can depend on you. It has to be reciprocal arrangement. (Reichstadt et al. 2007)

The prospect of *getting care when needed* which was for some older persons rather annoying was perceived by others as comforting and hence they welcomed it:

> If necessary, it is good to know that you can receive help from the social and health services - such as help with housework, a community nurse, a personal security alarm or transport etc. (Bergland and Narum 2007)

3.4.1.4 Satisfaction of Being Cared for

The desire of being cared for was satisfied when older persons *felt that they were supported by others*—either by their own children or by neighbours and friends (Shearer and Fleury 2006; Bergland and Narum 2007; Reichstadt et al. 2007; Hambleton et al. 2008; Musselwhite and Haddad 2010; Söderhamn et al. 2013; Stephens et al. 2015; Lette et al. 2017). Such support could be practical—e.g. taking an older person who had no car shopping—or just emotional by simply listening to his or her needs.

> But our children are out there now. That's a big sort of security blanket around here. They ring up in the morning; they ring up in the night. The girls will call up, all three of them so they're constantly in touch with me and if anyone of us is sick we don't have to ring up everyone. (Stephens et al. 2015)

Tangible support was not always necessary to create a feeling of being cared for. It was sufficient to know that it was *possible to get help when needed*. For this reason mobile phones were welcomed as they provided the opportunity to call for help. For a similar reason older persons felt sheltered at home, even if they had to take care for themselves (Fisher 1995; Green et al. 2005; Bergland and Narum 2007; Shrestha and Zarit 2012). It implied a possibility of help and support which could be reinforced by technical aids.

> It is important to feel safe in your own home […] I feel much safer after having installed a burglar alarm. (Bergland and Narum 2007).

In this way, staying at home allowed for a balance between the opposite needs for self-reliance and being cared for.

The desire of being cared for was, however, not always satisfied. Some older persons complained about feelings of *insecurity through information* that was distributed by the media. They did not know what to believe when they heard different messages about health and food (Gustafsson and Sidenvall 2002). Others *felt exposed to threats* in their environment as they perceived danger from local vandals, groups of youth or gangs, damage to property, burglars, and personal attack (Gabriel and Bowling 2004; Rudman and Durdle 2009; Stephens et al. 2015).

3.4.2 Exerting Influence on Others Versus Attention to the Needs of Others

Since nobody can be absolutely self-reliant and independent from others, older persons lived in relationships that were supportive to some extent. Receiving support from others could, however, result in feelings of dependency and eventually powerlessness. In order to counteract these feelings older persons tried to influence and sometimes even to control others. Such attempts could of course restrict the independence of those on whom the older persons had to rely and provoke their resistance. Being aware of this, older persons also showed a tendency to refrain from making demands on others and to pay attention to their needs.

3.4.2.1 Exerting Influence

The desire to exert influence on others was apparent as older persons wanted *to stay in control if they received help*. As one older person who received help at home put it:

> So she'd make a plan based on what she thinks is necessary, but she won't overrule me, she always tells me what she's going to do and why, and I like that. That way, you're respected as a person and that's very important to me. (Lette et al. 2017)

This desire to control was also obvious in societies with a strong tradition of filial piety like Nepal. Here older persons expected *to be respected by their family* and this respect was shown by caring for them when they needed support. Being dependent on the help of others should not diminish their patriarchal status and authority.

> The family used to honour them like the god. Need not to mention that. Son, daughter, grandchildren - everyone genuinely respected them from their heart. (Shrestha and Zarit 2012)

A desire to exert influence on others was also apparent when no support was required. Establishing social relationships with other persons required accepting their peculiarities, but some older persons expressed a *low tolerance* for these peculiarities and were inclined to demand that others behave according to their ideas of social standards (Pettigrew and Roberts 2008).

3.4.2.2 Satisfaction of Exerting Influence

Some older persons were able to *maintain their self-determination while receiving care* or support from others (Haak et al. 2007; Lette et al. 2017). If they only received the help they asked for they felt that they could exert control and manage on their own as in the case of an almost blind women who was supported by her children:

> Yes, I do what I want. And nobody comes and interferes in what I do … The children accept it and they come and see to the larder for me sometimes (Haak et al. 2007)

Other older persons experienced a *restricted self-determination when they received care* from others. If they engaged a home help service they felt that the organization controlled appointments and routines and that they were in the hands of those who performed the activities for them because they could not influence the quality of activity performance (Haak et al. 2007). One might expect that such experiences are absent in traditional societies like Nepal where care by the family is said to be the norm. However, even there patriarchal authority is likely to decrease. Shrestha and Zarit (2012) reported cases of older persons who had been abandoned by their family and were forced to stay in a nursing home. Becoming care dependent meant for them a loss of self-determination. Similar observations were made in other developing countries and we will turn to their reason in Chap. 4 where we describe the experience of older persons in long-term care settings.

There were also other circumstances that resulted in restricted self-determination which always depended on the chance to limit the influence of others on one’s own life. Some older persons complained about a *restricted control under medical treatment* because they felt that they had to obey to the medical doctors (Leung et al. 2004). *Being dependent on public transport* triggered similar feelings, because they had to observe the timetable, and to spent time waiting which was something they were not used to when they had a car of their own (Haak et al. 2007; Rudman and Durdle 2009; Stephens et al. 2015). When communities offered a transportation service older persons did not have choices about what time to be picked up and hence they experienced this service as intrusive on their freedom (Haak et al. 2007). If transportation was difficult to find they had the feeling of being trapped in their own place (Rudman and Durdle 2009; Musselwhite and Haddad 2010; Stephens et al. 2015). *Lack of money* was also associated with feelings of restricted control as it prevented older persons from using public transport and doing activities they liked to do (Stephens et al. 2015). In all these cases older persons felt that external circumstances determined the way how they could shape their way of life.

Finally, some older women also experienced a *restricted self-determination due to their spouse* since they were dominated by their partner who prevented them from having a life of their own. In some cases their husband was also care dependent and they felt the moral obligation to care for him:

> My life changed completely after my husband became chronically depressed a few years ago. I think I have a cheerless life. He dislikes my using the phone; doesn't want me to go out. I never imagined I would be so unhappy at this point in life. (Bergland and Narum 2007)

Not surprisingly, these women felt that they *regained self-determination after the death of their spouse* (Dale et al. 2012).

3.4.2.3 Attention to the Needs of Others

The desire for self-assertion was counterbalanced by a tendency to pay attention to the needs of others. In Western societies where people live in nuclear families older persons did not want to bother their children who lived in a separate household. They *feared to become a burden* and often claimed that they preferred to move into nursing home in case of being helpless (Söderhamn 1998; Bowling et al. 2003; Gabriel and Bowling 2004; Borglin et al. 2005; Bergland and Narum 2007; Rudman and Durdle 2009; Sundsli et al. 2013a: Lette et al. 2017).

> You have to be grateful for the children you have, but you can't have any claim to the children because they have their families and their lives (Borglin et al. 2005)

> I don't want to be a burden on my family when I get worse, however. I should prefer to move to a nursing home close to where they live so that they can visit me. (Bergland and Narum 2007)

Fear to become a burden was also the reason why some older persons were reluctant to ask their neighbours for help—even it was just a little favour:

> You can't ask other people to take you out for "a drive". They'd think you'd lost… [your] senses. Anyway they have got better things to be doing with their time (Musselwhite and Haddad 2010)

Attention to the needs of others was also apparent in the way how some older persons shaped their social relationships with neighbours and peers. Instead of feeling disturbed by their peculiarities they developed an *increased tolerance* (Dunn and Riley-Doucet 2007; Kalfoss 2010).

> With age, I have become more tolerant. Maybe this has something to do with being interested or one simply gets smoother around the edges with time. (Kalfoss 2010)

3.4.2.4 Satisfaction of Attention to the Needs of Others

One might expect that the desire to pay attention to the needs of others can easily be satisfied as it just requires that older persons restrain demands they put on others. Some older persons, however, were not able to meet this desire because they felt that they needed more support than others could provide and hence perceived themselves *to be a real burden* (Rudman and Durdle 2009).

3.4.3 Social Adjustment Versus Unconventionality

Since persons always live in some kind of relationship with others, their behaviour is attuned to that of others. As the sociologist Mead (1967) pointed out, persons anticipate the reactions of others and adjust their own behaviour to their anticipated responses. Throughout their process of socialization they internalize reactions of others to their own behaviours and develop in this way a notion of the expectations that others usually have regarding their behaviour. They learn to perform roles that fit into particular social environments. In each situation they shape their own behaviour according to what is commonly considered to be appropriate. They have, in other words, a tendency to social adjustment and conformity and do what everybody else does. Without this performance of social roles according to common standards the behaviour of a person would not be predictable for others. Persons are therefore determined by the roles they perform in social contexts. At the same time, however, such role performance makes persons aware that they are not confined to these roles. Just like an actor who plays a certain role is not identical with this role they can also behave in other ways and perform other roles. Hence, the aspect of their personality, which is behind the performed roles, remains undetermined. It is the spontaneous and unconventional part of the self that is unaffected by social norms and may even resist to them. Since social norms restrict this spontaneous part of the self, social adjustment and conformity have to be counterbalanced by a tendency to unconventionality. Unconventionality, however, can only be understood in its relationship to social norms and conventions, since it consists of a negative relationship to them.

3.4.3.1 Social Adjustment

Although only rarely mentioned by older persons there were indications that they made efforts *to observe social norms*. An indecent behaviour that violated social standards was not considered to be appropriate. Good manners were an essential part of their social identity. As one older man put it:

> If you practice good manners and good behaviour, you will not run into trouble. (Dunn and Riley-Doucet 2007)

3.4.3.2 Satisfaction of Social Adjustment

Adjustment to social norms gave them the *feeling to do the right thing* and to meet social standards (Dunn and Riley-Doucet 2007). Such adjustment concerned not only the behaviour but also the outer appearance of the older persons. For this reason some older women observed a diet and *felt guilty when they broke their diet* (Gustafsson and Sidenvall 2002). As we will see in Chap. 4, a lack of social adjustment may become an issue for older persons with functional limitations that prevent them from observing table manners and social standards of hygiene.

3.4.3.3 Unconventionality

Social adjustment had to be counterbalanced by a tendency to unconventionality. If people would only live their lives according to social norms, everybody would just reproduce the same patterns of behaviour and act in the same way as everybody else. One-sided conformity alienates a person from herself. Persons, however, also have a desire to be themselves. They want to be spontaneous and to distinguish themselves from others. For this reason, older persons also had a tendency to unconventionality and wanted to ignore social rules, because they had had to observe them throughout their working life and felt that now the time had come to get rid of self-imposed restrictions. Retirement gave them the chance *to do what they liked to do* (Bowling et al. 2003; Bauger and Bongaardt 2016).

> When you're working you have to compromise in many areas, and I'm delighted to be free of all that. I feel […] it's easier to be myself, that is, to find your own strengths and weaknesses and to have the time to evaluate them compared to when you're in a system (Bauger and Bongaardt 2016)

> If I decide I'm going to spend all day in bed and have bacon and eggs at 2 a.m., and go on holiday, or have a new suit, I can do them. Freedom for material things… Freedom from pressure. (Bowling et al. 2003)

Such unconventionality did not mean to break out of society, but to pursue an individual way of life within a framework of available options—even if some members of the society might feel disturbed by this way. In some cases, this attitude was also apparent in the consumption of food. Eating what they liked even if social norms declared it to be unhealthy was one way of being unconventional (Gustafsson and Sidenvall 2002).

3.4.3.4 Satisfaction of Unconventionality

The desire for unconventionality had its intrinsic satisfaction. Being impulsive and spontaneous made older persons feel happier (Kalfoss 2010) and freedom from duties and social pressure allowed them *to enjoy a life without undue restraints* (Söderhamn 1998; Gabriel and Bowling 2004; Söderhamn et al. 2011; Sundsli et al. 2013b).

3.4.4 Closeness Versus Distance

Social relationships are ultimately motivated by a desire for closeness. Closeness is the source for getting support and protection, finding entertainment and acceptance from others. The desire for closeness is therefore an essential human need. Too much closeness, however, may restrict a persons' privacy, independence, and unconventionality since being together with others makes it necessary to pay attention to their needs and to adjust to social norms. Persons have therefore the tendency to counterbalance closeness by distance. Distance, however, is just another kind of a social relationship. Since distance is always a distance from others, a relationship to others still exists when these others are absent. Even hermits can only withdraw from a society if there is a society from which to withdraw.

3.4.4.1 Closeness

The search for closeness had various degrees. In a broad sense it just meant a *desire for social participation.* Older persons wanted to share social life by staying up to date through the news (Söderhamn et al. 2011; Kwok and Tsang 2012) or by maintaining the feeling that they were still a part of the society (Musselwhite and Haddad 2010). Mainly, however, the orientation towards closeness meant a search for direct contacts (Farquhar 1995; Fisher 1995; Söderhamn 1998; Bowling et al. 2003; Gabriel and Bowling 2004; Leung et al. 2004; Green et al. 2005; Bergland and Narum 2007; Hambleton et al. 2008; Kalfoss 2010; Reichstadt et al. 2007; Smith 2012; Boggatz 2013; Söderhamn et al. 2013; Stephens et al. 2015; Lette et al. 2017)

> What is important in old age is that one tries to meet others in some sort of social relationship…. It is cheering to meet others (Kalfoss 2010)

Older persons *searched for contacts* in social gatherings organized by senior centres, parishes, and other kinds of social organizations (Bergland and Narum 2007; Hambleton et al. 2008; Boggatz 2013; Stjernborg 2017). Whereas such gatherings did not require a particular commitment, some older persons preferred to have the obligations and advantages of a binding *group membership* (Dunn and Riley-Doucet 2007; Boggatz 2013; Sundsli et al. 2013b). Such groups allowed them to pursue their preferred hobby, to practice their faith, or to find support in dealing with their diseases. Other older person disliked group meetings at all and tried to *maintain individual contacts* with peers and friend by visits or informal meetings where they had tea or coffee (Wilhelmson et al. 2005; Musselwhite and Haddad 2010; Reichstadt et al. 2010; Boggatz 2013; Sundsli et al. 2013b; Bauger and Bongaardt 2016). Of central concern, however, was the *attachment to the family* and—if he or she was still alive—to the spouse (Gabriel and Bowling 2004; Leung et al. 2004; Borglin et al. 2005; Wilhelmson et al. 2005; Moore et al. 2006; Musselwhite and Haddad 2010; Sundsli et al. 2013a; Bauger and Bongaardt 2016).

> I can call upon my daughter … which I am sure enhances my quality of life, because I think… friends are very good friends, but you can't call upon people unless you know them terribly well […] you really need family for that. (Gabriel and Bowling 2004)

> I met my husband when we went to school… Since then we've stuck together the whole time, in fact, and been married for 55 years, he's a wonderful man … he's been in and out of hospital but somehow you get closer to each other (Borglin et al. 2005)

To meet their desire of a close relationship after the loss of a spouse, some older persons tried *to find a new partner* who sometimes could also satisfy their desire to be cared for:

> I'm old now, but I still have interest in women. This is why: Because without a woman in a house we lose everything. When you are sick, you need a woman to care for you (Stephens et al. 2015)

3.4.4.2 Satisfaction of Closeness

Older persons who were still married expressed the satisfaction of their desire for closeness by describing their *happiness with the spouse*.

> We have a great time and mind our own business (Borglin et al. 2005)

Those searching for new partners sometimes got satisfied from *romantic relationships* with the opposite sex:

> My wife was a good talker, we talked, we schemed, and we laughed. That's why the lady I see is important. She's like my wife. It makes a terrible difference. (Hambleton et al. 2008)

Getting the *attention from family and friends* was the most important source of social satisfaction for those who were widowed, and grandchildren could bring a special joy to their life (Fisher 1995; Bergland and Narum 2007; Reichstadt et al. 2007; Pettigrew and Roberts 2008; Kalfoss 2010; Sundsli et al. 2013a, b; Bauger and Bongaardt 2016):

> When you get feedback, kind of, and she thinks it's nice to meet me and I think it's nice to meet her, then you get a transfer of emotions. (Bauger and Bongaardt 2016)

> My children are incredibly kind and caring, and although none of them live here in Oslo, we keep in touch regularly….What is the greatest pleasure? My grandchildren …They are my friends, they keep me quick-witted, and they are a great inspiration to me. (Bergland and Narum 2007)

Family gatherings with joint meals were a particular occasion to experience such closeness and they also gave a deeper meaning to the consumption of food because they allowed sharing pleasure with others (Gustafsson and Sidenvall 2002; Pettigrew and Roberts 2008). Getting attention was closely associated with the satisfaction of the desire to be cared for. A number of older persons described how their children and their friends provided both practical and emotional support (Bergland and Narum 2007; Kalfoss 2010: Söderhamn et al. 2011)

> Friends have taught me a lot about coping with illness, long before I became sick. I have learned about coping with small and more serious things (Kalfoss 2010)

In such cases, both needs that have been separated here for analytical purpose were experienced as a unity by older persons. Beside such close contacts, however, many older persons also had more superficial acquaintances that satisfied their need to socialize. They had a *gain of contacts* through their participation in group activities organized by a senior centre or a parish (Bergland and Narum 2007; Pettigrew and Roberts 2008; Dale et al. 2012: Boggatz 2013; Stephens et al. 2015; Stjernborg 2017). *Chance encounters* with someone they knew also satisfied their need for closeness to some extent (Musselwhite and Haddad 2010). If they lacked such opportunities they tried to satisfy their need for closeness by getting *attention from substitutes*. This could be a paid home helper who became part of the household after some time (Hambleton et al. 2008; Pettigrew and Roberts 2008), but it could also be a pet (Bowling et al. 2003; Pettigrew and Roberts 2008; Söderhamn et al. 2011; Smith 2012).

However, the desire for closeness remained several times less or even unsatisfied. Some older persons felt *excluded from participation* in social activities due to financial limitations (Borglin et al. 2005). Others reported how they *tried to avoid feelings of loneliness by distracting* themselves with reading, working, or watching television (Pettigrew and Roberts 2008). In some cases there was also a *lack of suitable contacts* despite the availability of opportunities. In order to establish relationships it was not enough to bring people together, they also had to feel mutual sympathy and share some interests:

> There is a local old folks' centre, but I am not that sort of person to go and talk to other old people, complaining about this and that. I just don't want that, I would rather die (Pettigrew and Roberts 2008)

Social isolation could become worse due to illness or the loss of old friends and some older persons suffered seriously from *loneliness* (Farquhar 1995; Bowling et al. 2003; Gabriel and Bowling 2004; Hambleton et al. 2008; Pettigrew and Roberts 2008; Boggatz 2013; Stephens et al. 2015; Lette et al. 2017) which was described in one study as living in a vacuum or being in a prison (Smith 2012).

> I'm very lonely. It is so hard in this day and age –everybody is just so busy and they don't have time for the little things (Pettigrew and Roberts 2008)

> No hand to hold… . Socially I am a person nongrata, being seen by other wives as a threat. (Bowling et al. 2003)

Such feelings were particularly strong when older persons *grieved for the loss of a partner* or spouse (Farquhar 1995; Bowling et al. 2003; Gabriel and Bowling 2004; Hambleton et al. 2008; Pettigrew and Roberts 2008; Kalfoss 2010; Smith 2012; Boggatz 2013).

3.4.4.3 Distance

The desire for closeness was counterbalanced by a *need for temporary distance* which was welcome, provided one could socialize again (Dale et al. 2012; Söderhamn et al. 2013). Other older persons had an even stronger desire for privacy and *preferred to be alone* (Borglin et al. 2005; Green et al. 2005):

> Mostly I'm alone and I think it's all right, it is. And since I like reading, if I hadn't done that I don't know what I would have done (Borglin et al. 2005)

Beside the need for privacy there were also other reasons for searching some distance. Some older persons *disliked groups* because of their social rules; others expressed a *limited need for contacts* because they disliked the gossip in social gatherings (Boggatz 2013). Some older persons felt too old to find new friends and preferred superficial contacts (Gabriel and Bowling 2004); others *rejected contacts at all* because they had become intolerant to others (Pettigrew and Roberts 2008). In such cases, the satisfaction of an exaggerated need for distance produced a dissatisfaction of the opposite need for closeness and made older persons suffer from loneliness.

3.4.4.4 Satisfaction of Distance

Nearly nobody, however, complained that the desire for distance remained unsatisfied. Living at home made sure that older persons had enough distance, and those who searched for it *enjoyed their privacy*.

> I enjoy being alone, very much! I like making a good meal and enjoy the food and a nice glass of wine in my own company. I was used to having other people around me all the time, but now I have learned to appreciate solitude. (Dale et al. 2012)

Some older persons, however, who had to accept home help perceived the presence of a foreign person as an *intrusion into their privacy* (Haak et al. 2007). This issue is of even greater concern for older persons in residential long-term care we will see in Chap. 4.

3.4.5 Influencing Factors

3.4.5.1 Physical Condition

The satisfaction of social orientations was influenced by the older person's physical condition. Deterioration of health and functional limitations did not only have a negative impact on the satisfaction of body-related needs, they also prevented older persons from maintaining contacts as they desired (Pettigrew and Roberts 2008; Smith 2012).

3.4.5.2 External Circumstances

Such limitations were sometimes compensated and sometimes aggravated by external circumstances. Suitable *housing conditions* could provide a feeling of security and comfort (Stephens et al. 2015) and even promote social contacts. Older persons in Sweden described how the elevator in their apartment block made it easy to go out and meet neighbours and friends (Green et al. 2005). A *safe environment* where they did not have to worry about crime encouraged older persons to leave their home, whereas an unsafe environment reduced this desire (Bowling et al. 2003; Gabriel and Bowling 2004). Socializing also depended on the *social climate* in the neighbourhood. There were older persons who complained about how this climate had changed and how they missed the old days:

> We had very nice times down there (in the common garden). We had long tables and a barbeque and… but it is not like that anymore, and it will never be like that again because … those youths, they do not stick together. They could go down there and have a barbeque, but they don't. So that won't be [happening] anymore. (Stjernborg 2017)

The search for opportunities to meet other persons could also be hampered by a limited *access to information* about available programs and facilities (Bryant et al. 2004). Some older persons tried to find such information in the media, preferably on paper, for instance, from the municipality, community centres, etc., but also in the internet (Lette et al. 2017). Others depended in this matter on persons in their environment. Preferred sources of information were the own children, friends but also foreigners who appeared to be trustworthy like general practitioners (Lette et al. 2017). Senior centres, congregate meal sites, and programs in the nearby surroundings provided an easy *access to contact opportunities* (Shearer and Fleury 2006; Söderhamn et al. 2011) whereas a lack of such facilities or a long distance to reach them were an apparent obstacle (Gabriel and Bowling 2004; Bergland and Narum 2007; Hambleton et al. 2008; Pettigrew and Roberts 2008; Stjernborg 2017). *Transportation facilities* could alleviate the problem of long distances if they were available. Some older persons still owned a car (Gabriel and Bowling 2004; Musselwhite and Haddad 2010) while others had given up driving and depended on public transport which was sometimes experienced as convenient and sometimes as uncomfortable (Gabriel and Bowling 2004; Bryant et al. 2004). Older persons in rural areas complained about a lack of such opportunities that restricted their opportunities to socialize (Rudman and Durdle 2009; Stephens et al. 2015).

> I like uniting with my children but always restricted as no transport. So mostly I would just stay home. So end up usually never leave the house and just live by myself alone in the house. (Stephens et al. 2015)

Some communities had established pick-up busses or call-a-ride transportation systems. These were perceived as helpful (Rudman and Durdle 2009) but also as cumbersome and expensive (Smith 2012). Older persons stressed that *sufficient income* was a necessary precondition for social well-being as it allowed for paying for transport to and participation in social activities (Bowling et al. 2003; Gabriel and Bowling 2004; Leung et al. 2004; Borglin et al. 2005; Wilhelmson et al. 2005; Bergland and Narum 2007; Reichstadt et al. 2007; Bryant et al. 2004; Larson et al. 2009; Kalfoss 2010; Söderhamn et al. 2011; Dale et al. 2012; Stephens et al. 2015;

Lette et al. 2017). The desire for closeness and being cared for could also be satisfied by *access to assistance*. This could be, for example, an attendant who visited older persons and accompanied them for long walks or on public transport (Stjernborg 2017). A paid home help provided beside practical support also a chance to socialize (Lette et al. 2017). The most important source for such assistance, however, was *support from their own children* if they lived in the same area and had a good relationship to their parents (Fisher 1995; Bergland and Narum 2007; Reichstadt et al. 2007; Pettigrew and Roberts 2008; Kalfoss 2010; Sundsli et al. 2013a, b).

3.4.6 Behavioural and Attitudinal Reactions

In order to satisfy their social orientations of action older persons pursued a variety of social activities. *Going out* to meet family, neighbours, and friends allowed them maintaining social contacts and participating in social life (Bowling et al. 2003; Dunn and Riley-Doucet 2007; Larson et al. 2009). Many *joined gatherings* in senior centres, parishes, or societies (Bergland and Narum 2007; Hambleton et al. 2008; Boggatz 2013; Stjernborg 2017). *Grand parenting* Green et al. 2005; Sundsli et al. 2013a) and *volunteering* (Pettigrew and Roberts 2008; Dale et al. 2012; Kwok and Tsang 2012) were further sources of satisfaction of social needs. *Using communicative devices*, mainly telephone but also the internet, was helpful for this purpose (Kalfoss 2010; Söderhamn et al. 2011; Kwok and Tsang 2012). *Dealing with pets* and *watching television* could supplement and sometimes also substitute social contacts (Pettigrew and Roberts 2008; Larson et al. 2009; Kwok and Tsang 2012; Smith 2012).

Sometimes such compensative behaviour was associated with a change of attitudes. Instead of searching for social contacts older persons became rather oriented to social distance. They made little or no attempts to connect to others and *withdrew socially* (Hambleton et al. 2008). This, however, did not necessarily result in feelings of loneliness. Withdrawal could enable them to find an inner balance if they focused on identity- or development-related orientations of action that strengthened their self-acceptance and hope, as it will be seen in the following sections. Exaggerated withdrawal, however, could also result in *escapism* which was difficult to overcome. Some older persons reported how they resorted to the consumption of alcohol to ease grief after the loss of a spouse.

> When my wife died I took refuge in alcohol. Now I no longer drink a lot. I got in such a state with alcohol that I knew I had to do something about it. It wasn’t easy. I drank spirits, whisky I drank. Now, I don’t drink spirits (Pettigrew and Roberts 2008)

Another example for a readjustment of opposite social needs concerned reducing the desire to influence others and increasing the tendency to pay more attention to their needs by *calming oneself down* when feeling upset by their behaviour. To “put up with things” enabled older persons to avoid social conflicts and maintain positive relationships (Dunn and Riley-Doucet 2007).

A way to find closeness in partnership despite restricted sexual potency was to resort to an *intimacy without sexuality* (Kalfoss 2010). In this case, re-orientation from sexual desire to sexual abstinence helped older persons to satisfy their desire for closeness. A way to overcome the loss of a spouse was to *accept life as it was* and to look forward despite grieving:

> … my first husband was killed in a road accident, and my second husband, he sat and died suddenly … you've got to accept that these things have happened, and you've got to move on. I think so anyway … I mean there's some people [who say] 'Oh, she'll never get over that'. Well you never do get over it but if you can accept it you can start taking the steps, you've got to … life's got to go on, hasn't it? (Gabriel and Bowling 2004)

Such acceptance was an orientation of action that was related to one's personal development as we will see in the one after next section. In order to remain independent and self-reliant several older persons tried to find strength in their own *resilience* and they expressed a strong will not to give up. Having experienced tough periods and events earlier in life was viewed as an internal resource, because they had gained wisdom and strength (Fisher 1995; Gabriel and Bowling 2004; Haak et al. 2007; Moore et al. 2006; Söderhamn et al. 2013).

> I never thought all this struggling was good, but now at this age I can see it has its advantages. To get up and struggle a bit and make a decision and hope you are right. It's very important to living (Moore et al. 2006)

Exaggerated trust in one's own resilience, however, may result in an overestimation of functional capacities and even as a *denial of beginning care dependency*. A social worker, for instance, remembered cases of older women who made him doubt their ability to take care of themselves:

> You know, it's just remarkable how often I hear older people say that everything is fine. For instance this blind woman, 92 years old and with several disabilities, she says: 'Well, I still do my own grocery shopping, but not when it's slippery during winter, I don't dare to risk it.' Well, you wonder, who does it for her when it's slippery? A friend of hers, who's also 90. And she says: 'Yes, everything is fine, I don't need anything, all is going well.' And when I asked: 'What if something happens to your friend, what then?' Well, it seemed she's never even thought about that. (Lette et al. 2017)

Such denial, as we will see in the one after next section, is just like the above-mentioned escapism a development-related orientation of action.

3.5 Quality of Life and Identity-Related Orientations of Action

Social orientations of action as described in the previous section concern the way how older persons relate to others. As persons, however, older people do not only have a relationship with others, but also a relationship with themselves. As we saw in the first chapter, a person is an "entity for which, in its Being, that Being is an issue" (Heidegger 1962, p. 236). Since one's own being is not determined, persons must give it a content. They have to shape their identity. Human beings are aware of their own existence as a field of possibilities and choices. These possibilities are of course restricted by the circumstances of their lives, but human beings are not determined by drives and instincts that come into a balance automatically. Even if they obey most of the time to habits and routines in shaping their lives they cannot avoid making their own decisions that make them the persons they are. Persons are ultimately in charge of themselves.

Persons shape their identity by relating to the material world around them. They do so by working and being productive and this identity-related orientation of action has to be counterbalanced by mental relaxation. Work gives a deeper meaning to physical activity which is quite often involved in it. Mental relaxation is related to physical rest in a similar way. In their relationship to the world persons also search for diversion and entertainment which must be counterbalanced by a tendency towards reflection, since an excess of entertainment may become trivial and insignificant.

Since persons do not simply exist for themselves, but can only become persons through their relationship with others, they also have to shape their identity through these relationships. If their life was an end in itself it would be meaningless. To fill their lives with content, people show concern for others. Since concern for others may result in self-neglect, it has to be counterbalanced by self-centredness. In order to gain a social identity persons have to create an image of themselves in the eyes of others. They do so by self-presentation that has to be counterbalanced by self-concealment. Self-presentation implies furthermore self-perception. As social actors, persons need to have an idea about the self they want to represent. They obtain this idea through a positive self-perception that reflects their desired self-image, and through a critical self-perception that draws their attention to their deficits, prevents a biased self-satisfaction and thus counterbalances their positive self-perception.

Identity-related orientations of action add a level of meaning to social orientations of action. Social orientations of action are not ends in themselves; they are involved in the process of shaping one's identity. Closeness is a means for self-presentation and it allows at the same time to get entertainment and diversion. Distance on the other hand supports the tendency to self-concealment and allows for reflection. Exerting influence and control in social relationships is necessary to promote one's self-concern whereas attention to the needs of others becomes meaningful if older persons also have an altruistic concern for others that gives meaning to their life. Being self-reliant in social relationships is a precondition for a positive self-perception and for work and productivity, whereas the satisfaction of the desire for being cared for meets the need for mental relaxation and is associated with a critical self-awareness of one's own capabilities.

Figure 3.5 shows the identity-related orientations of action in the context of physical conditions, external circumstances, and behavioural and attitudinal responses. Table 3.4 details the aspects of these categories which will be explained in the following. As in the previous sections, these aspects are shown in italics.

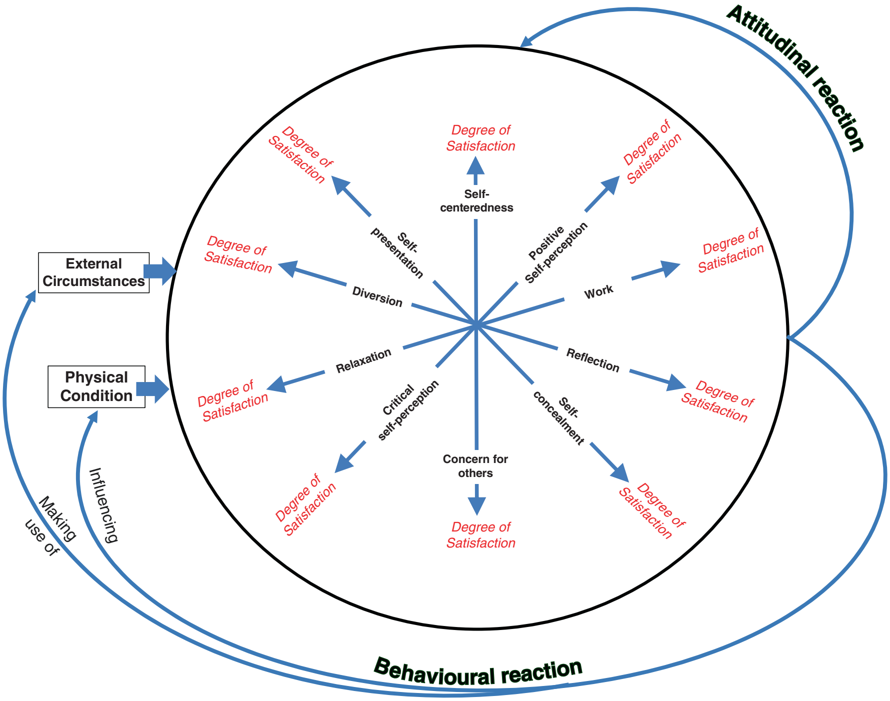

Fig. 3.5 Identity-related orientations of action

Table 3.4 Identity-related orientations of action, influencing factors, and coping strategies

Orientations of action and their satisfaction	
Work	Eagerness to remain active
	Continuing to work in the previous job
	Commitment to leisure activities
Satisfaction of work	Feeling busy
	Stimulation through activities
	Being absorbed by activities
	Satisfaction with work results
	Boredom
Relaxation	Taking a break
	Desire to relax Desire for tranquillity
Satisfaction of relaxation	Feeling relieved from burdensome activities
	Enjoying the environment
	Enjoyment of nature
	Feeling stressed

Table 3.4 (continued)

Diversion	Searching for entertainment
	Desire for having joy and fun
	Desire for distraction
	Passive consumption
Satisfaction of diversion	Being entertained
	Lack of stimulation
Reflection	Desire for intellectual challenge
	Pursuing individual interests
	Maintaining cognitive integrity
Satisfaction of reflection	Intellectual satisfaction
Concern for others	Taking care of the family
	Desire to care for other people
	Social initiative
Satisfaction of concern for others	Feeling useful and needed
	Feeling useless
Self-centredness	Balance between concern for others and self-interest
	Avoidance of social responsibilities
	Self-concern
	Self-neglect
	Reduced self-concern
Satisfaction of self-centredness	Self-reward
	Relief from self-sacrifice
	Worries about others
	No satisfaction of own needs at all
Self-presentation	Being appreciated and respected by others
	Expressing social status
	Refusing to be stigmatized
Satisfaction of self-presentation	Receiving respect from others
	Losing respect from others
Self-concealment	Staying in the background
Satisfaction of self-concealment	Satisfied if remaining unnoticed
Positive self-perception	Efforts to maintain a positive self-image
	Comparing own situation with situation of others
Satisfaction of positive self-perception	Self-confidence
	Feeling of not being old
	Positive memories
	Loss of self-esteem
Critical self-perception	Realistic self-assessment
Satisfaction of critical self-perception	Self-acceptance despite limitations

(continued)

Table 3.4 (continued)

Influencing factors and coping strategies	
Physical condition influencing identity-related orientations of action	*(same as under body-related orientations of action)*
External circumstances influencing identity-related orientations of action	Housing condition
	Safe environment
	Social climate
	Access to information
	Access to contact opportunities
	Transportation
	Sufficient income
Behavioural and attitudinal reactions	Domestic work/gardening/shopping
	Working
	Hobbies
	Singing/dancing
	Parlour games
	Watching TV/listening to the radio
	Using the internet
	Playing lotto
	Travelling/excursions
	Reading/crosswords
	Studying
	Visiting cultural events
	Grand parenting/volunteering
	Thinking positive
	Downward comparisons
	Reminiscence

3.5.1 Work Versus Relaxation

Shaping the world by work is an essential expression of human identity. Persons become what they are by what they do. Work is self-realization. Excessive work, however, may result in self-abandonment, as it is the case with workaholics. To protect their identity, persons also need detachment from work and relaxation.

3.5.1.1 Work

After retirement, older persons wanted to be busy in order to fill their day. They were *eager to remain active* even with restricted abilities (Gabriel and Bowling 2004; Wilhelmson et al. 2005; Bergland and Narum 2007; Reichstadt et al. 2007; Söderhamn et al. 2013; Sundsli et al. 2013a).

> Quality of life is based on everyday tasks. It feels good to have set tasks and to feel able to perform them. It's important to use your skills and abilities. Even if you're not part of the working population any more, it's still important to find ways of employing your skills, so that you don't feel left out. (Bergland and Narum 2007)

For some older persons staying active meant *continuing to work in their previous job*. One of them told how he once had wanted to be taken off the sick list in order to return to his job.

> I think that if you have satisfaction in your job, you will become healthier. I have a chronic disease, and I think it is very important not to sit down… Then I informed the physician that I was working full time and asked if it was a right choice. OK, you are working … I suspected it, he said, and so he took me off the sick list. (Söderhamn et al. 2013)

Those who had given up working after retirement nevertheless showed a *commitment to leisure activities* that required some skills and provided a sense of achievement (Fisher 1995; Söderhamn 1998; Bowling et al. 2003; Gabriel and Bowling 2004; Infantino 2004; Leung et al. 2004; Borglin et al. 2005; Moore et al. 2006; Bergland and Narum 2007; Dunn and Riley-Doucet 2007; Reichstadt et al. 2007; Hambleton et al. 2008; Pettigrew and Roberts 2008; Larson et al. 2009; Kalfoss 2010: Reichstadt et al. 2010, Boggatz 2013; Stephens et al. 2015).

> It is important to have a hobby when you are retired, there is much to be engaged in even though it isn't work (Kalfoss 2010)

The choice of activities depended on individual preferences. It referred to pursuing hobbies but also included to take care of the household. Some older persons wanted to be socially involved and shared their hobbies and interests with others. Others preferred solitary activities like handicraft work or solving crosswords. Quite often, work required some physical effort and older persons with a desire for physical activity liked to satisfy this desire through work.

3.5.1.2 Satisfaction of Work

A commitment to activities yielded an intrinsic satisfaction. For some older persons it meant simply *feeling busy* and filling the day (Fisher 1995; Wilhelmson et al. 2005; Reichstadt et al. 2007; Smith 2012; Söderhamn et al. 2013). Sometimes they had a daily agenda they could barely meet:

> I find there are not enough hours in the day that I could get all the things done that I want to do. I'm busy probably close to 18 hours a day doing all kinds of things that I do. (Reichstadt et al. 2007)

Many older persons described a positive *stimulation through activities* (Wilhelmson et al. 2005; Larson et al. 2009; Musselwhite and Haddad 2010; Söderhamn et al. 2013; Stephens et al. 2015). To do things made them "happy and engaged" (Larson et al. 2009) and gave them a sense of mental fitness and vitality.

> Imagine thinking every morning: What will I do today? It is excellent!. (Söderhamn et al. 2013)

Some older persons described how they were sometimes completely *absorbed by their activities* and forget all other needs:

> I could work and work and work, suddenly at 4 am in the morning I'd discover I'm frozen… I'm hungry, I'm thirsty, I'm tired, I haven't known any of that because I've been concentrating… it's an intense thing, and when I'm working on them, I'm working on them and nothing else gets done really. (Green et al. 2005)

A further experience that motivated older persons to spent efforts in activities was the *satisfaction with work results*:

> I prefer to stay in my garden (…) The nice thing is when you seed flowers and see how they grow and later on you see the success. (Boggatz 2013)

On the other hand, those who were unable to pursue their desired activities complained about *boredom* due to a lack of activity (Smith 2012).

3.5.1.3 Relaxation

The desire for mental engagement was counterbalanced by a need for mental relaxation. This need had different degrees. For some older persons it meant just *taking a break* and relief some stress in order to get involved in activities again (Söderhamn et al. 2013). Others had a *desire to relax* more permanently and gave up responsibilities perceived as burdensome in order to free energies for activities that promoted their well-being (Borglin et al. 2005). There were also those who had an explicit *desire for quietness and tranquillity* —sometimes because coping with diseases took their energy (Boggatz 2013), sometimes just because they felt no need to be active and searched for inner calmness (Dunn and Riley-Doucet 2007).

3.5.1.4 Satisfaction of Relaxation

These desires were satisfied when the older persons *felt relieved from burdensome activities* (Borglin et al. 2005), did nothing in particular and just *enjoyed the environment* by watching the life around them (Farquhar 1995; Gabriel and Bowling 2004; Musselwhite and Haddad 2010; Dale et al. 2012):

> I like the sunshine - I don't care for the wind if I can sit on my chair on the balcony in the sunshine, I can sit and read, and watch the people go by… see the kids go by from school. (Farquhar 1995)

> I live my life at the balcony, from there I can see the green area and the sky and it feels so good (Green et al. 2005)

The *enjoyment of nature* had a particularly relaxing effect on the mind—even when physical activity like walking or gardening was involved in experiencing it (Söderhamn 1998; Infantino 2004; Knestrick and Lohri-Posey 2005; Bergland and Narum 2007; Musselwhite and Haddad 2010; Dale et al. 2012: Boggatz 2013)

> I like to watch the colors of the leaves changing, the blue skies, and winter days. These are all part of how God shows us his presence (Infantino 2004)

If, however, older persons were not able to satisfy their need for relaxation they *felt stressed*. This was the case when they lost physical strength or had to take over tasks from a sick or deceased partner they were not used to perform. For them, work in the household was not a pleasure but a burden that they could not avoid:

> Well there are some things like mowing the lawn. I can do them but I've found that with other jobs, you know, preparing meals, washing and, well, the old saying, 'A woman's work is never done'. You just don't always have the time and you've got to get down to the shops and that to get stores. (Hambleton et al. 2008)

3.5.2 Diversion Versus Reflection

Work keeps people busy and relaxation allows them to recover. Both, however, can become monotonous and boring. That is why older persons also have a desire for diversion. Entertainment, however, that meets this desire can be superficial and may produce a feeling of triviality. For this reason, diversion has to be counterbalanced by some reflection that allows a deeper understanding of the world.

3.5.2.1 Diversion

Older persons were *searching for entertainment* to get stimulation (Green et al. 2005; Bergland and Narum 2007; Boggatz 2013). This gave them a feeling of being connected with life. Participation in social gatherings was a convenient way to achieve this goal. Such gatherings did not have to provide a program. Having a chat with others was sufficient. Other older persons told about their *desire for having joy and fun* and their love for singing or dancing—either together with other persons or alone (Moore et al. 2006; Boggatz 2013)

> I love to dance, I'd dance till I starved myself if I could. (Moore et al. 2006)

The need for stimulation became also apparent in a *desire for distraction* when older persons were alone. Some of them reported how they kept the television running just to have some noise in the background (Smith 2012). There were also some older persons who were inclined to a *passive consumption*. They felt that they were unable to take any initiative in order to find entertainment by themselves. They rather believed that such opportunities had to be offered in a program and they would just have to choose what suited them.

> We are not able to choose, you should suggest something, she should tell us, we have to offer this… this…. this… and I could say yes, this… and this… (Boggatz 2013)

3.5.2.2 Satisfaction of Entertainment

The desire for entertainment was satisfied when older persons felt entertained by social gatherings (Borglin et al. 2005; Boggatz 2013; Stjernborg 2017). *Being entertained* gave a deeper meaning to the desire for closeness. Socializing with others, celebrating, singing, and dancing together raised the older persons' spirits. They gained energy and joy of life from engaging in social interaction. Visitors of a senior centre in Sweden, for example, described how such programs provided entertainment and allowed for a change:

> I think they are doing a nice job, both the municipality, Maria, and the ones with Christmas coffee, and then we have the celebration around Midsummer, and we are sitting outside. … yes, we went to the theatre, too. If it weren't be for them doing all this for us, we would just be sitting there [at home]. (Stjernborg 2017)

Listening to music, singing, or dancing conveyed an even stronger sense of *joy of life* (Borglin et al. 2005; Moore et al. 2006; Boggatz 2013)

> There's such good music at the gymnastics and I think it's such fun so I go there–ah, here comes that old girl again. (Borglin et al. 2005)

The desire for entertainment and stimulation was, however, not always satisfied. Some statements indicate that older persons suffered at least temporarily from a *lack of stimulation*. This occurred, for example, when they had given up driving.

> The lack of getting out and about is truly depressing. It makes you feel trapped… you can't get out and about to see anything, and yes, it has reduced my general enjoyment of life. (Musselwhite and Haddad 2010)

3.5.2.3 Reflection

There were also older persons who expressed a dislike for simple entertainment. Instead, they had a *desire for intellectual challenge* when they visited cultural events or socialized with other people (Hambleton et al. 2008; Boggatz 2013).

> There should be a certain quality (…) well, I would not go to an event, where I think, it is somehow… well, let's say, amateurish. (Boggatz 2013)

> …for example, to sit together and read a book und then to discuss it, so that people say, blimey, I read this book or that book, go and read it, borrow it, and then we talk about it. (ibid.)

Such inclinations, however, were not always shared by persons around them. As a consequence, they *pursued individual interest* like reading fine literature, studying history, or painting just for themselves (Borglin et al. 2005; Boggatz 2013).

But also those who had less intellectual or cultural demands were eager to engage mentally to some extent since it had functional benefits. *Maintaining cognitive integrity* was perceived as a prerequisite to preserve one's personality (Leung et al. 2004; Borglin et al. 2005; Bergland and Narum 2007; Kalfoss 2010; Dale et al. 2012; Söderhamn et al. 2013; Lette et al. 2017):

> I think when your mind deteriorates you'll be in trouble, and I hope I won't have to experience that. (Lette et al. 2017)

For these older persons, also less sophisticated activities provided a sufficient challenge:

> Play canasta, things like that are good because you activate your brain, you have to think a bit and that does no harm (Borglin et al. 2005)

3.5.2.4 Satisfaction of Reflection

The desire for reflection was met when older people found *intellectual satisfaction* (Bergland and Narum 2007; Boggatz 2013). Such satisfaction could be derived, for example, from reading a fine piece of literature, or from having a sophisticated discussion. Although not explicitly mentioned in any of the investigated studies, the above cited comments suggest that social gatherings for the sake of simple amusement and distraction were perceived by some older persons to be dull and trivial and did not meet their desire for reflection. As we will see in Chap. 4, older persons in residential facilities made such experiences when they had to participate in the facility's entertainment program.

3.5.3 Concern for Others Versus Self-Centredness

Since work and relaxation, diversion, and reflection may become ends in themselves, they are not sufficient to shape a person's identity. Being a person is only possible in a relationship with others. Hence, whatever persons do, they want to do it for someone. Concern for others is a way to find meaning in one's life and to shape one's identity. Quite often, it is related to the desire to work and to be productive, since others shall benefit from the effort spent on work. Being productive could be synonymous to be altruistic and to care for other persons. Altruism, however, could result in self-neglect and therefore had to be counterbalanced by some self-centredness. Of course, work and relaxation, diversion, and reflection can also be an expression of self-centredness.

3.5.3.1 Concern for Others

First of all, older persons *took care of their family*—either of their care dependent spouse, or of their children and grandchildren (Gabriel and Bowling 2004; Infantino 2004; Green et al. 2005; Moore et al. 2006; Shearer and Fleury 2006; Musselwhite and Haddad 2010; Sundsli et al. 2013a; Stephens et al. 2015; Stjernborg 2017).

> My children and grandchildren… My purpose is to try and set a good example for them and to provide a better way of living. (Moore et al. 2006)

> I pick up my granddaughter from school… I love doing that for my daughter and love being with my granddaughter. (Musselwhite and Haddad 2010)

Concern for others was, however, not restricted to the family. Quite often older persons expressed a *desire to care for other people* in the community. Some of them specified that such care consisted of emotional support and advice or even practical help when a friend was sick (Shearer and Fleury 2006; Dale et al. 2012; Bauger and Bongaardt 2016) whereas others remained rather unspecific about the nature of such care (Fisher 1995; Wilhelmson et al. 2005; Bergland and Narum 2007; Kalfoss 2010; Musselwhite and Haddad 2010; Sundsli et al. 2013a).

> One needs to care, care about others, care about your fellow man (Kalfoss 2010)

Boggatz (2013) identified two degrees of concern for others. Whereas some older persons were just occasional helpers, others showed a strong *social initiative* and volunteered regularly, for example, by collecting donations in the parish, visiting residents in nursing homes, or contributing actively to the programme of social afternoons. Such social initiative was also reported in other studies (Leung et al. 2004; Bergland and Narum 2007; Pettigrew and Roberts 2008; Reichstadt et al. 2010; Söderhamn et al. 2011; Smith 2012; Sundsli et al. 2013a; Stephens et al. 2015).

> I try and sort of meet people and do a lot of volunteer work now, I enjoy that. I am on the telephone at the Aged Person Support Service, been on that for 23 years (Pettigrew and Roberts 2008)

Whereas some of these older persons got involved in volunteering because they were asked to do so, others actively searched for occasions to be helpful after their retirement. In some countries there were agencies of civic engagement that arranged for voluntary work.

> It was always in my mind to go there [to the agency of civic engagement] (…) well, and then I searched in the directory for their address… and then I went there. (Boggatz 2013)

In some cases, older persons' concern for others did not focus on the immediate community but on the society as a whole and resulted in a religious or political engagement (Söderhamn et al. 2011; Sundsli et al. 2013a).

3.5.3.2 Satisfaction of Concern for Others

In any case, concern for others gave older persons a *feeling of being useful and needed* (Gabriel and Bowling 2004; Dunn and Riley-Doucet 2007; Pettigrew and Roberts 2008; Dale et al. 2012; Boggatz 2013; Söderhamn et al. 2013). Helping others was not expected to yield any profit. It had an intrinsic value and the immediate reaction of those receiving help was perceived as a source of joy. Such concern for others gave older persons a feeling of purpose in life.

> When I was busy working, I was an introvert, very quiet, just worked, paid bills. And all of that turned into what? And I came here … I've always wanted to help other people. I got the opportunity here. If I can do something for somebody and knowing that I'm not expecting nothing back, I'm doing it because I enjoy doing it and it makes me feel great inside (Reichstadt et al. 2010)

> To raise my spirit I need to help others, touching others with a smile makes you feel good. (Dunn and Riley-Doucet 2007)

Such feelings were closely associated to the satisfaction of the needs for closeness and acceptance by others (which we will be considered in the following section). If—on the other hand—older persons were not able to show concern for others, they *felt useless* and also lonely because nobody seemed to need them anymore (Smith 2012; Lette et al. 2017).

> I'm much better when I'm busy, doing things for people. That's all I've done all my life, so - you have to be needed. If you don't feel like you're needed, then you're in trouble. (Smith 2012)

3.5.3.3 Self-Centredness

Whereas some older persons said that caring for others was a necessary counterbalance to self-centredness and helped to increase their well-being (Söderhamn et al. 2013), others were aware that an exaggerated altruism would result in self-neglect and had to be counterbalanced by some egoism (Bauger and Bongaardt 2016). Both points of view concur that a *balance between concern for others and self-interest* was required.

Concern for others, however, was not equally pronounced in all cases. Some older persons were rather focused on self-concern. They wanted *to avoid social responsibilities* (Boggatz 2013; Sundsli et al. 2013a) and were not inclined to volunteer as they did not expect to find any pleasure in such a duty:

> Well, I can hardly imagine to go to a nursing home and read something to some of these grandmas (…) it should provide some pleasure (…) otherwise it would be a fulfilment of duties and I don't feel like doing that. (Boggatz 2013)

Others were less direct, but offered excuses for their lack of concern for others:

> Well, in any case I'm a bit afraid of obligations, I mean permanent engagement… and basically I'm not able to do this. (Boggatz 2013)

This tendency to self-interest was in some cases due to a lack of energy and physical strength. In other cases, women who had cared for their spouse felt relieved after his death and rediscovered their own needs they had neglected before (Boggatz 2013; Stjernborg 2017).

But also those who were inclined to care for others showed some *self-concern* (Wicks 2006; Hambleton et al. 2008; Söderhamn et al. 2011; Stephens et al. 2015). They recognized their own needs, did something for themselves by allowing themselves small pleasures, and accepted that at times their own needs might conflict with the needs of others, and tried to find a way in which all parties are satisfied and no one is hurt. One woman described such an enlightened self-interest in the following way:

> There is no devious, hidden agenda in me saying that I don't want you to come to me for that weekend. It is not that I don't love you, or I am cranky with you for any reason (…) It is just that I would rather do something else. (…) I also don't like to always do what somebody else thinks I should do. So, it is a nice little two bob each way, I suppose you could say. And it works. It works for me. I hope it works most of the time for the people I care about. (Wicks 2006)

On the other hand, there were also older women who had at least temporarily abandoned a healthy self-interest. Caring for a care dependent spouse caused them to adopt an attitude of *self-neglect* and they gave up to pursue own interests (Dale et al.

2012; Stjernborg 2017). But also losing a beloved person they had been caring for could result in *reduced self-concern* as it diminished the older women's sense of being needed which gave them a reason to care for themselves. Widows who consumed food without pleasure and interest because there was no one else who needed their cooking (Gustafsson and Sidenvall 2002) are an example for this attitude and their body-related orientation to food abstinence has to be understood as an expression of reduced self-interest.

3.5.3.4 Satisfaction of Self-Centredness

When older person satisfied their self-interest they experienced some kind of *self-reward*. Such reward could be a simple pleasure like a piece of chocolate or a tasty meal (Gustafsson and Sidenvall 2002; Stephens et al. 2015), but also a new cloth or a visit to the hairdresser (Söderhamn et al. 2011). Older women who had cared a long time for their husband could experience widowhood despite initial grief as a *relief from self-sacrifice* (Dale et al. 2012; Stjernborg 2017)

> I have had a great life after being widowed. Earlier, I always had to think of my husband first and last, I was tied up and had few possibilities for self-attendance and spare time. I was completely self-sacrificing. When I was widowed it was suddenly different, I was myself, at last! (Dale et al. 2012)

Older persons who could not satisfy their self-interest were too much involved in *worries about others* (Gabriel and Bowling 2004; Borglin et al. 2005; Bergland and Narum 2007; Stjernborg 2017). Worries included problems of their children like poor health or marital break-ups, responsibility for older relatives, and of course the needs of a care dependent spouse. If such burden became too strong older women felt that they could get *no satisfaction of their needs at all* (Bergland and Narum 2007; Dale et al. 2012; Stjernborg 2017).

3.5.4 Self-Presentation Versus Self-Concealment

Shaping one's identity also requires self-presentation. As we saw in the previous section, persons cannot develop an identity without playing a social role. If a person existed only for herself, she would have no social identity. She would not even be a person, since her existence would not be reflected in the eyes of others. In order to obtain a social identity it is not enough to adjust to social norms. Adjustment results in conformity and if everybody would behave like anybody else persons would lose their individual qualities and could not be distinguished from each other. Like every person, older persons wanted to be recognized for their unique qualities. They wanted to be seen by others and to get their attention and respect. Showing concern for others was one way to achieve this goal, and seen in this way, altruism could also satisfy self-interest. However, persistent attention from others may unmask a person and reveal aspects of her character that she would rather keep to herself. It may expose her to gossip that harms her social reputation and results in a loss of respect.

For this reason, the desire for self-presentation was counterbalanced by a tendency to self-concealment. The avoidance of public attention allowed older persons to remain undisturbed and to protect their privacy. Hiding aspects of oneself behind a social role is a necessary aspect of self-presentation, since it allows social actors to determine which aspects of themselves they want to reveal and which aspects not. Adjustment to social norms has the same function. It produces a façade that allows concealing aspects of the inner self that are deemed to be unsuitable for self-presentation. If, however, a person permanently stays in the background and is inclined to complete self-concealment, she remains unnoticed and loses her social identity. In order to get attention and to gain the respect of others, persons have to find a balance between self-presentation and self-concealment.

3.5.4.1 Self-Presentation

Like anybody else, older persons wanted *to be appreciated and respected by others*; they wanted to be acknowledged as a unique person having her own worth—even if they had lost some of their abilities (Gabriel and Bowling 2004; Bergland and Narum 2007; Pettigrew and Roberts 2008; Kalfoss 2010). They wanted to be recognized as someone special.

> My quality of life means that others are glad that I exist (Kalfoss 2010)

> It is important that you are respected for your dignity or individuality. As you start losing your resources and your health, you depend on more people … you start losing independence. (Shearer and Fleury 2006)

Another way to find respect from others was *to express one's social status*. Driving a car could serve this purpose and allowed older persons visibly demonstrating their youthfulness at the same time (Musselwhite and Haddad 2010). For the same reason they *refused to be stigmatized* as old. Some of them expressed their dislike if people spoke about "the elderly" in generic terms (Bergland and Narum 2007) and some were reluctant to use technical aids like walkers as they could be seen by others as a sign of reduced competence and frailty (Haak et al. 2007).

3.5.4.2 Satisfaction of Self-Presentation

If older persons succeeded in presenting themselves, they *received respect from others* who recognized their positive qualities (Infantino 2004; Shearer and Fleury 2006; Kalfoss 2010; Söderhamn et al. 2011, 2013; Sundsli et al. 2013b; Lette et al. 2017).

> Sometimes I meet people I haven't seen in a long time and they say you look so well. This makes me happy. (Kalfoss 2010)

Others, however, described how they had *lost the respect of others* due to their age and how they suffered from ageism (Larson et al. 2009; Kalfoss 2010; Lette et al. 2017).

> I feel misunderstood, one doesn't count in society anymore, others feel that you aren't of value. (Kalfoss 2010)

3.5.4.3 Self-Concealment

Not every older person, however, had a desire to get the attention of others. There were also those who preferred to *stay in the background*. If, for example, these persons were asked to play an active role in arranging social afternoons for seniors, they claimed that they lacked the abilities to do so since they had only a low education and they were afraid that their peers might interpret such coming to the fore as a sign of arrogance (Boggatz 2013).

3.5.4.4 Satisfaction of Self-Concealment

As these findings suggest, older persons were at least to some extent *satisfied if they remained unnoticed* and did not stand out from the crowd. The tendency not to attract attention meant that older people did not talk much about it in the interviews.

3.5.5 Positive Versus Critical Self-Perception

Self-presentation is impossible without self-perception. Social actors need to have an idea about the self they want to present in social interaction, but this idea in turn is influenced by the reaction of others to their self-presentation. Getting the attention and the respect of others may contribute to a positive self-perception. A negative self-perception in turn may trigger efforts to get acknowledgement from others in order to compensate a loss of self-esteem. Self-perception is, however, not determined by the reaction of others. Persons strive for a positive self-image regardless of what others might think about them. They shape their self-image according to their wishes, and even if they experience disrespect from others, they do not necessarily give up their positive self-perception. However, people can adopt criticism from others and start to engage in self-criticism. To some extent, this may be an adequate counterbalance to a one-sided self-praise, but an exaggerated self-criticism may also undermine their self-esteem.

3.5.5.1 Positive Self-Perception

On the one hand older persons made *efforts to maintain a positive self-image* (Borglin et al. 2005; Bergland and Narum 2007; Dunn and Riley-Doucet 2007; Kalfoss 2010) As one of them put it:

> It is important to have a positive picture of yourself (Kalfoss 2010)

To gain a positive self-image, some older men partook in competitive games and wanted to get satisfaction from winning:

> I enjoy the competitiveness. It's like a life over death challenge. (Dunn and Riley-Doucet 2007)

> I have every intention of being around and not letting it beat me. (ibid.)

While this seemed to be a rather male attitude among active agers, other older persons just wanted to reach a desired level of activity in order to obtain a positive self-image.

(Borglin et al. 2005). In a similar way, *downward comparisons with the situation of others* who were worse off made older persons feel that they could meet their own standards—even if they achieved less than originally desired (Farquhar 1995; Bowling et al. 2003; Gabriel and Bowling 2004; Kalfoss 2010; Bergland and Narum 2007).

> Seeing other people who are not well makes me feel lucky that I still have good health. (Bowling et al. 2003)

3.5.5.2 Satisfaction of Positive Self-Perception

Successful efforts to maintain self-acceptance gave older persons a feeling of *self-confidence*. They were satisfied from winning in competitions, or felt pride when they had solved a task they had perceived as a challenge like repairing something in their house or growing plants in their garden or catching fishes (Söderhamn 1998; Moore et al. 2006; Dunn and Riley-Doucet 2007; Hambleton et al. 2008; Bauger and Bongaardt 2016). Helping others was a further way to boost their self-acceptance as it was a proof of their still existing capabilities (Kalfoss 2010; Söderhamn et al. 2011).

> When I help others, I receive help myself. I bring confidence to the other as well as to myself. (Kalfoss 2010)

They also could derive some sense of accomplishment from their physical condition, for example, if they felt in good health or still had their teeth (Dunn and Riley-Doucet 2007) Others described their positive self-acceptance as a *feeling of not being old* even if they had grown old outside (Fisher 1995; Moore et al. 2006; Reichstadt et al. 2007).

> Well, you can refer to me as being an older person, but I don't think of myself as being older because I feel vigorous. I feel I don't look upon myself as being older. (Moore et al. 2006)

Positive memories about past achievements were another source of a positive self-image (Borglin et al. 2005; Moore et al. 2006; Kalfoss 2010; Reichstadt et al. 2010; Söderhamn et al. 2013; Sundsli et al. 2013a).

> I remember all sorts of things, my whole life, all the journeys we've made, when we did this and that. That gives pleasure because that's something nobody can take away from you (Borglin et al. 2005)

Some older persons, however, described how they *lost their self-esteem* since they could not achieve the desired level of cherished activities or had to abandon them completely. Having to give up driving was such an incidence:

> It's hard to explain I suppose. You just don't seem like you belong. I suppose yes there are feelings that you might be ready for the scrapheap now. The first step to it, you know. (Musselwhite and Haddad 2010)

3.5.5.3 Critical Self-Perception

Despite their need for a positive self-perception, older persons were aware that one-sided self-praise would result in self-delusion. A somewhat critical self-perception was a reasonable counterbalance as it allowed them to be aware of their age-related weaknesses and limitations. It resulted in a realistic self-assessment (Reichstadt et al. 2010; Dale et al. 2012; Sundsli et al. 2013a)

> You may have to modify. Your own image of yourself is still that of somebody in their 20's or 30's or 40's. You got to realize you are not and still actually say 'ok, it is all right.' And then modify; suit your desires to what is realistic. (Reichstadt et al. 2010)

3.5.5.4 Satisfaction of Critical Self-Perception

A realistic self-assessment made older persons aware that there was no need to be perfect in order to satisfy the desire for a positive self-perception. It enabled them to find *self-acceptance despite limitations* (Reichstadt et al. 2010; Dale et al. 2012; Sundsli et al. 2013a)

> You take it as it comes. And you take into consideration—you soon learn what you can and cannot do. And it takes me longer to write a letter and I'm certainly not as sharp mentally as I once was. And I see deterioration there. But you cannot worry about it because that is life. (Reichstadt et al. 2010)

Self-acceptance based on such critical self-awareness immunized older persons against criticism of others and gave them the strength to be what they were:

> … and then she said to me: 'oh, now your hair looks so untidy'. And then I said: 'Yes, I am aware of that. But you know what? I am so happy to have hair at all'. (Dale et al. 2012)

3.5.6 Influencing Factors

The satisfaction of identity-related orientations of action depended on the same influencing as the satisfaction of social orientations. Comfortable *housing conditions* and a *safe environment* supported mental engagement and relaxation. A positive *social climate*, *access to information and to contact opportunities* did not only help older persons to socialize, as already mentioned above, it also gave them the opportunity to find acceptance from others and to satisfy their need for entertainment. *Transportation facilities* and *sufficient income* were necessary prerequisites for all kind of individual and social activities.

3.5.7 Behavioural and Attitudinal Reactions

Older persons satisfied their need to work by a variety of activities. *Domestic work*, *gardening*, and *shopping* kept them busy (Infantino 2004; Green et al. 2005; Dunn and Riley-Doucet 2007; Hambleton et al. 2008; Pettigrew and Roberts 2008; Larson et al. 2009; Söderhamn et al. 2011; Kwok and Tsang 2012; Boggatz 2013). Sometimes they were still *working* as an employee or they were self-employed (Kwok and Tsang 2012). Others tried to be productive by pursuing individual *hobbies* such as arts or handicrafts (Bowling et al. 2003; Leung et al. 2004; Green et al. 2005; Kwok and Tsang 2012; Smith 2012; Sundsli et al. 2013a).

Singing or *dancing* together with other people was a way to satisfy the need for entertainment and diversion (Kalfoss 2010; Dale et al. 2012; Kwok and Tsang 2012). *Parlour games* provided entertainment at social gatherings (Borglin et al. 2005; Larson et al. 2009; Kwok and Tsang 2012; Smith 2012; Sundsli et al. 2013a), *watching television*, *listening to the radio*, and sometimes *using the internet* fulfilled this purpose when they were alone (Pettigrew and Roberts 2008; Larson et al. 2009; Kwok and Tsang 2012). Some older persons also derived some pleasure and excitement from *playing lotto* which offered a theoretical chance to make some profit (Stephens et al. 2015). *Travelling* abroad was a challenging way to find entertainment, *excursions* to the closer environment a more convenient one (Sundsli et al. 2013a; Boggatz 2013).

Those who were inclined to intellectual activities and reflection told that they liked *reading* (Borglin et al. 2005; Pettigrew and Roberts 2008; Larson et al. 2009; Söderhamn et al. 2011: Dale et al. 2012; Kwok and Tsang 2012; Sundsli et al. 2013a). Doing *crosswords* was another way to meet this desire and gave older persons also a feeling of being productive. Some satisfied their desire for intellectual activities by *studying*. They learned foreign languages or took courses in music, art, philosophy, or in dealing with computers (Kwok and Tsang 2012; Boggatz 2013). *Visiting cultural events* like theatre or concerts provided entertainment and an opportunity for reflection for those who had higher demands (Kwok and Tsang 2012; Boggatz 2013).

Grand parenting and *volunteering* allowed older persons to show concern for others and find their acceptance (Leung et al. 2004; Green et al. 2005; Pettigrew and Roberts 2008; Dale et al. 2012; Kwok and Tsang 2012; Boggatz 2013; Söderhamn et al. 2011, 2013; Sundsli et al. 2013a).

A strategy to maintain a positive self-perception in the face of adversities was *downward comparisons* (Farquhar 1995; Bowling et al. 2003; Gabriel and Bowling 2004; Kalfoss 2010; Bergland and Narum 2007). Realizing to be better off than many others helped to downsize own problems.

> Seeing other people who are not well makes me feel lucky that I still have good health (Bowling et al. 2003)

Another source for self-acceptance was positive memories. *Reminiscence* was helpful to find inner strength as it reminded the older persons to their achievements in life and made present problems seem to be insignificant (Borglin et al. 2005; Moore et al. 2006; Kalfoss 2010; Reichstadt et al. 2010; Sundsli et al. 2013a).

> I remember all sorts of things, my whole life, all the journeys we've made, when we did this and that. That gives pleasure because that's something nobody can take away from you (Borglin et al. 2005)

3.6 Quality of Life and Development-Related Orientations of Action

The final level of orientations of action concerns the temporality of existence. Whereas all previously described levels provided a still-image of a current situation, real life is like a motion picture as it unfolds in the course of time. Living in the presence means to relate to the past in order to look forward to the future. To experience a good quality of life requires a balance between these two orientations. Because all other orientations of action have been developed in the past and are maintained or changed in the future, they are all affected by the balance between attachment to the past and searching for new perspectives. Attachment to the past provides a sense of continuity and is essential for having a personal identity. People's life consists to a large extent of their routines and habits, which they have acquired in the past. An excessive attachment to such routines, however, can lead to stagnation and prevent future development. Hence, searching for new perspectives is essential for personal growth. Development, however, does not always occur due to an inner drive to change habits and routines. Throughout their lives human beings have to face adversities. Older persons experience diseases and losses and they know that their condition may become even worse. They can react to these adversities and risks in two different ways. To some extent they can try to ignore them by denial in order to protect an optimistic outlook on life, but they may also decide to face them in order to plan ahead and manage them. In the face of adversity and loss, older persons have furthermore to tendency to hope which allows them to overcome adversities by discovering something positive in a negative condition. This tendency, however, has to be counterbalanced by some scepticism that prevents older persons from being credulous.

Figure 3.6 shows these development-related orientations of action. To symbolize their relationship with the other levels of orientations the latter are depicted in the middle. Table 3.5 lists their aspects and kinds of satisfaction. Also here, aspects listed in this table are shown in italics.

3.6.1 Attachment to the Past Versus Searching New Perspectives

3.6.1.1 Attachment to the Past

On the one hand, older persons had an attachment to their past. They wanted *to maintain their habits and routines* (Hambleton et al. 2008; Larson et al. 2009; Sundsli et al. 2013a; Stephens et al. 2015).

> Well one becomes a creature of habit in that one does not want the modern; one proceeds in the old tracks (Larson et al. 2009)

> I always get my hair done on a Friday, and I do my shopping, and my daughter picks me up and we have lunch. Then she brings me home with my groceries and takes me to the hairdresser at one o'clock. (Hambleton et al. 2008)

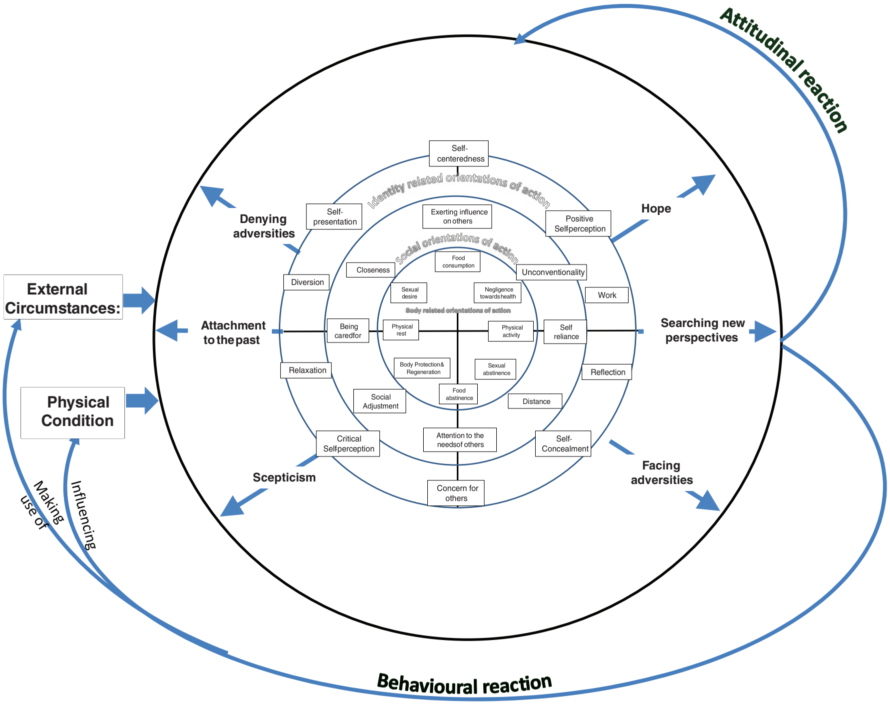

Fig. 3.6 Development-related orientations of action

Table 3.5 Development-related orientations of action, influencing factors, and coping strategies

Orientations of action and their satisfaction	
Attachment to the past	Maintaining habits and routines
	Desire to remain at home
	Cultivation of memories
	Declined interest in old habits
Satisfaction of attachment to the past	Satisfaction from maintaining habits
	Disturbances in daily routines
	Missing old habits
	Loss of the familiar world
Searching new perspectives	Looking forward to changes
	Desire to discover new things
	Facing new challenges
	Change in continuity
	Learning new things if relevant
	Dislike to learn new skills
Satisfaction of searching new perspectives	Discovering new possibilities
	Discovering something new in the familiar
	Stagnation

(continued)

Table 3.5 (continued)

Denial of adversities	Avoiding unnecessary worries
	Carelessness about the future
	Problem denial
Satisfaction of denial of adversities	Belief to be satisfied
	Fear of losing one's identity
	Sudden fear of death
Facing adversities	Taking precautions
Satisfaction of facing adversities	Being prepared for adversities
Scepticism	Downsizing expectations
Satisfaction of scepticism	Becoming detached from losses
Hope	Thinking positive
	Religious beliefs
	Individual spirituality
Satisfaction of hope	Appreciating small things and living in the moment
	Self-growth by overcoming crises
	Inner peace and harmony
	Religious comfort
	Hope for resurrection
	Depression
	Doubt and Despair
Influencing factors	*(same as under body-related, social, and identity-related orientations of action)*
Behavioural and attitudinal reactions	Religious practices
	Meditation *(attitudinal reactions are the same as development-related orientations of action)*

According to their habits they preferred to be active or relaxed, withdrawn or socially engaged, concerned about themselves or others, and so on. What mattered in any case was that they could continue their life as it used to be. For the same reason they had a strong *desire to remain at their home*, because this was the place that was shaped according to their taste and that allowed them to live according to their habits and routines (Gabriel and Bowling 2004; Borglin et al. 2005; Green et al. 2005; Wilhelmson et al. 2005; Bergland and Narum 2007; Haak et al. 2007; Dale et al. 2012; Söderhamn et al. 2013; Stephens et al. 2015; Lette et al. 2017). It was their familiar life-world, filled with memories, and provided independency and safety at the same time. As a self-made environment it protected and preserved their identity. As one of them said:

> Being at home and coming home is like putting on a cosy coat or cardigan (Green et al. 2005)

Living in such an environment also encouraged the *cultivation of memories*. Reminiscence kept them connected to their past and, as mentioned in the previous section, allowed them to maintain a positive self-perception (Borglin et al. 2005; Moore et al. 2006; Kalfoss 2010; Reichstadt et al. 2010; Sundsli et al. 2013a).

Sometimes such memories referred to things or traditions that had been inherited from ancestors and should be passed on to the next generation. One older woman, for example, grew flowers in her garden that once belonged to her mother:

> They were plants passed on to me by my mother. She had the irises for about 30 years. I have had them for about 30 years also. It encourages me to do the same with my daughter. It's like perpetuating oneself and brings back cherished memories (Infantino 2004)

And another older woman recalled how she made a traditional national costume for her oldest grandchild's confirmation ceremony:

> The feeling that this is something you're giving to a grandchild and she'll have it for the rest of her life […] That's a good feeling, compared to embroidering a national costume and selling it to someone you don't know. (Bauger and Bongaardt 2016)

Other older persons, however, reported a *declined interest in old habits*, because they did not yield the same pleasure as they used to do or because they had lost their meaning as was the case with the women who gave up cooking after the death of their spouse (Gustafsson and Sidenvall 2002). As one older person put it:

> There are things that one lets go as time passes by. (Sundsli et al. 2013a)

3.6.1.2 Satisfaction of Attachment to the Past

As long as the older persons could perform their usual way of life they felt *satisfied from maintaining their old habits* (Hambleton et al. 2008; Sundsli et al. 2013b). Others, however, had to accept change due to declining health. Some complained about *disturbances in their* daily routines because they had to employ a home help which they also felt to be an intrusion into their privacy (Haak et al. 2007). Others *missed old habits* that they had been used to perform throughout their life (Hambleton et al. 2008; Stephens et al. 2015)

> Yeah I miss, I will miss that, and I'm getting slowly worse and I will continue to worsen so yeah… There a period of mourning like giving up the entertainers. I really, really enjoy singing and acting and I'm going to have to give it up very soon. (Stephens et al. 2015)

The loss of a spouse, finally, was experienced as *loss of a familiar world*, because widowed persons missed the security of daily routines that married life had provided (Smith 2012).

3.6.1.3 Searching for New Perspectives

On the other hand, older persons were also inclined to change. Some of them were eagerly *looking forward to changes* in the future and were even ready to give up their usual life. They had enrolled on a waiting list for a sheltered flat and associated the new living arrangement with making new experiences and finding new friends and even moving to a nursing home was perceived by some of them as a possible solution in case of growing care dependency (Dale et al. 2012; Söderhamn et al. 2013; Lette et al. 2017).

Other older persons did not want to change their life completely. Change meant for them a *desire to discover new things* in order to broaden their horizon (Gabriel and Bowling 2004; Infantino 2004; Wicks 2006; Bergland and Narum 2007: Reichstadt et al. 2007; Söderhamn et al. 2011; Söderhamn et al. 2013; Sundsli et al. 2013a, b). They attended educational classes, tried to learn new skills or travelled abroad to see foreign cultures. Such activities did not only meet the above-mentioned desires for diversion and reflection, they were also associated with a process of growth and development:

> Every time we do something new, it is a new adventure and you have to learn new skills and you have to be adventurous. So I have reinvented myself a dozen times and this is a new reinvention … and it suits fine. (Reichstadt et al. 2010)

Discovering new things meant to break out of everyday routines and to feel alive which was easily achieved if older persons had a car and were still able to drive.

> That's what the car does you see. Takes you where you don't need to go, you see. And for me that's life. Not just day-to-day stuff, not just living to survive, but what else can be on offer, going beyond survival – seeing real life, a painting, a forest, the sea (Musselwhite and Haddad 2010)

Some older persons were also inclined to *face new challenges* that required learning new skills and made them somewhat nervous. One woman, for example, told how she considered accepting an offer to be a board member in a social club:

> That's something I really want, but at the same time it's frightening. That is … of course it is. But then I think, ok, what's the worst thing that could happen? (Bauger and Bongaardt 2016)

Since new challenges could be too demanding, some older persons preferred to *change while maintaining continuity*. For them, pursuing a long-cherished hobby or interest like gardening provided the opportunity to learn new things:

> I like flowers and like learning about the different types of leaves and the habit of growth. (Infantino 2004)

Other older persons pointed out that their desire to learn new skills was related to something that they perceived to be a meaningful extension of their familiar life world. They wanted *to learn new things if these were relevant* in the context of their usual life. For this reason, some of them expressed a dislike to learn how to handle a laptop or computer (Stephens et al. 2015). Since the opportunities offered by these devices (e.g. emailing) were of little or no relevance to their daily lives or to the pursuit of their personal interests, the time spent on learning how to use them was perceived as a waste. Some older persons even expressed a *dislike to learn new skills*—for example, when the own children suggested the use of new technologies:

> You know what my son did, he came and put a lap top here and one whole month we went to a computer class and then we discovered our necks were getting stiff, our shoulders were getting sore and then I told my husband, if he wanted to send an email or anything just to get the boys to do it. Why more work? Forget it. So that's how we gave up the computer. (Stephens et al. 2015)

3.6.1.4 Satisfaction of Searching for New Perspectives

The desire to change was satisfied when older persons *discovered new possibilities in their life*. This occurred when they developed new interests, or learned a new skill like, for example, painting (Infantino 2004) or when they tried to stay up-to-date with new technologies like the internet (Sundsli et al. 2013a). Those who strove to change while maintaining continuity were able *to discover something new in the familiar* (Infantino 2004; Reichstadt et al. 2010):

> For those that are active, they are growing whether they realize it or not—they're still growing. They still enjoy going to a movie. They still enjoy sleeping with people. They enjoy good food. That is all growing. You know they're not sitting in their rooms … waiting for something to happen. (Reichstadt et al. 2010)

Although no older person who participated in the investigated studies complained about *stagnation*, some of them were aware that this would be the result if they got stuck to a repetition of old habits and were not able to discover something new in their lives.

> Contentment I think can lead to stagnation. (Reichstadt et al. 2010)

As we will see in Chap. 4, some older persons who lived in long-term care facilities suffered from stagnation.

3.6.2 Denial of Adversities Versus Facing Adversities

When older persons strove for continuity and change as described above they tacitly assumed that life would go on as usual. Change could result in an extension of the familiar world, but it did not require abandoning it completely. Quite often, however, this tacit expectation was not met. Older persons became aware of their growing health risks and had to go through painful experiences like a serious illness or the loss of a spouse. Denial of possible or real adversities allowed to some extent to maintain an inner balance.

3.6.2.1 Denial of Adversities

For some older persons, ignoring adversities simply meant *to avoid unnecessary worries* (Borglin et al. 2005; Bergland and Narum 2007: Reichstadt et al. 2007; Hambleton et al. 2008; Kalfoss 2010; Reichstadt et al. 2010; Lette et al. 2017). According to them, there was nothing to regret in the past and no reason to think about possible problems in the future.

> Not dwelling on what you could have been or forgot to do or could not do or things you want to do that are no longer capable of it. Just being content. (Reichstadt et al. 2010)

> It's not that I'm evading the responsibility, it's just that I think it's a waste to worry about things you won't be able to do anything about anyway, not right now at least. (Lette et al. 2017)

Some of these older persons were aware that this attitude implied *carelessness about the future*.

> We are egoists, we take all for granted and don't think that things will happen to us, nor how we will cope when it happens. (Kalfoss 2010)

> But there are dreamers - and I belong to them, to these emotional people who cannot really judge what is missing, and in this case only good luck can help. (Boggatz 2019)

This careless attitude prevented them from thinking about what they might do if they should become frail and care dependent. They knew about assisted living and nursing homes, but they did not consider making use of these options.

> You know, it's like that as long as it goes halfway, you don't want to think about it. That's a big mistake, but it's like that. (Boggatz 2019)

Behind such avoidance to make arrangements in advance was the idea that there was no alternative to a nursing home in case of care dependency since older persons did not want to become a burden for their children while at the same time moving to a nursing home meant giving up independence and the familiar way of life. Having no solution for this problem they preferred not to think about it.

The avoidance of worry, however, was not feasible when older persons were confronted with illness, loss of a spouse, or the prospect of their own dying. In such moments some of them resorted to *problem denial*, which was—as we saw in the previous sections—an attitudinal reaction if orientations of action could not be satisfied. Fear of diagnosis could prevent older persons from visiting a doctor (Leung et al. 2004), fear of losing their self-reliance could result in a denial of care dependency (Lette et al. 2017; Boggatz 2019), and loss of a spouse could result in escapism and provoke excessive consumption of alcohol in order to forget (Pettigrew and Roberts 2008). In the same way thoughts about own death were rather avoided (Leung et al. 2004; Borglin et al. 2005).

3.6.2.2 Satisfaction of Denial of Adversities

Older persons who focused on living in the present were less concerned about age-related limitations and—as long as there was no serious threat to their usual way of life—they were satisfied due to their *belief to be satisfied*:

> Health is based on attitude; if you believe you are healthy then you feel healthy and, therefore, are not old. (Knestrick and Lohri-Posey 2005)

The optimistic attitude enabled a positive self-assessment. It may, however, turn out to be a self-deception that dissolves when serious adversities arise. In fact, not everybody succeeded in maintaining such a positive outlook on life. Some older persons were afraid that declining physical strength might force them to abandon old habits and they told about their *fear to lose their identity* if they had to move into a nursing home where they were deprived of the only place that had protected their identity (Gabriel and Bowling 2004; Hambleton et al. 2008; Boggatz 2019).

> I mean I often think well, what is there to look forward to, in old age? … It can be frightening if you think about it, you think of all these people and friends of course that have been ill […] the thing which would frighten me the most would be going in a home. … I don't ever want to have to do that, having had … relatives – my mother went in a home. … I don't think their quality of life was very good … mentally they were both extremely alert … but their bodies were just dying. (Gabriel and Bowling 2004)

Others admitted how they were overcome by a *sudden fear of death* despite their avoidance to think and talk about it (Leung et al. 2004; Borglin et al. 2005).

> You don't think about it normally but all of a sudden you stop and you think, well, you'll soon be dead, I think … I think, you know, that I don't want to think about it but I do anyway, what it's like, you know, to die. (Borglin et al. 2005)

Such moments made them feel helpless and reinforced their tendency not to think about their dying.

3.6.2.3 Facing Adversities

Not everybody, however, was inclined to avoid thinking about possible adversities and threats. There were also those who *took precautions* and moved into an independent living facility since they saw the day coming when they would need help.

> If you can't care for yourself any longer […] then I'm already more prepared for it. I'm already there and everything in this house is handicapped accessible […] early enough you have to start […] imagine that I would have to move in when I am 80. (Boggatz 2019)

For the same reason, some older persons put themselves on a waiting list of a nursing home.

3.6.2.4 Satisfaction of Facing Adversities

As the quotation above suggests, taking precautions forced older persons to deal with the unpleasant aspects of ageing, but they were *prepared for adversities* and could not easily be upset when something happened (Boggatz 2019).

3.6.3 Scepticism Versus Hope

In the face of adversities older persons had two options. On the one hand, they were sceptical about a positive development in the future, and tried to adapt to a given situation and to reduce their expectations. Since such a sceptical attitude could result in negative feelings they also had to find some hope and to discover something positive in the negative.

3.6.3.1 Scepticism

Downsizing expectations was a way to adapt to losses and physical decline (Fisher 1995; Söderhamn 1998; Gabriel and Bowling 2004; Haak et al. 2007; Reichstadt et al. 2010). It meant to give up cherished activities and to become content with what still remained.

> Reading a newspaper … it's too complicated to turn the pages and hold it, you know, I'm used to, have always been able to read very fast … I can't now, I don't want to anymore (Haak et al. 2007)

This attitude was associated with a modification of self-perception since it required older persons to become aware of their limitations. Scepticism corresponded to a desire to be free of illusions. This concerned also religious expectations which were considered to be illusionary by atheists. We will encounter this attitude in the fifth chapter where we investigate quality of life in the process of dying. However, in the studies about the perspective of independently living older adults that were investigated here it was surprisingly not mentioned.

3.6.3.2 Satisfaction of Sense of Scepticism

Downsizing expectations was accompanied by some sadness, but on the long run it helped older persons to *become detached from their losses* and they learned to accept them as a part of their life (Gabriel and Bowling 2004; Reichstadt et al. 2010). As one older person put it:

> You've got to develop a reasonable philosophy, otherwise you're just going to be bitterly disappointed all the time, and that's part of life's training … if you still think that the world owes you a living, and that everything is going to turn out right, then you're always going to be disappointed, if things go wrong … they'll go wrong, so that's a good attitude to have. … There's no need to get depressed about it, it's just a fact of life.
>
> (Gabriel and Bowling 2004)

3.6.3.3 Hope

Scepticism had to be counterbalanced by tendency to hope that allowed to overcome adversities. Quite often, older persons talked about their inclination *to think positive* and to make the best out of things even if this seemed to be difficult sometimes (Fisher 1995; Söderhamn 1998; Bowling et al. 2003; Gabriel and Bowling 2004; Leung et al. 2004; Borglin et al. 2005; Knestrick and Lohri-Posey 2005; Moore et al. 2006; Wicks 2006; Bergland and Narum 2007; Dunn and Riley-Doucet 2007; Reichstadt et al. 2007, 2010; Kalfoss 2010; Söderhamn et al. 2011; Dale et al. 2012; Sundsli et al. 2013a).

> I compare my life with a caramel, I have the caramel in my mouth, I suck the best out of it, and spit the rest away (Kalfoss 2010)

> The way I see it, a good quality of life comprises both positive and negative experiences. The positive experiences speak for themselves. The negative ones might be difficulties you face; they turn into something positive when you are able to deal with them. Failing to deal with them means they will become bad memories. (Bergland and Narum 2007)

Other older persons tried to find hope and to overcome adversities by religiosity. They sought guidance from religious teachings and practiced their *religious belief*, for example, by praying or going to the church as it is common among Christians (Knestrick and Lohri-Posey 2005; Dunn and Riley-Doucet 2007; Söderhamn et al. 2011). There were also those who had no religious affiliation, but were inclined to *individual spirituality* that allowed encountering a deeper dimension of reality that gave meaning to their life (Bergland and Narum 2007; Reichstadt et al. 2010). Such spirituality did not necessarily imply faith in God or a transcendent power; it could just mean the tendency to discover the positive sides of life despite all its negative aspects.

> I think that good 'quality of life' depends on your spiritual qualities and ability to use them in a positive way as long as you have the strength…. I think what is most important is to be satisfied with what you get in life. (Bergland and Narum 2007)

3.6.3.4 Satisfaction of Hope

Older persons who had to cope with losses, diseases, or functional limitations became aware of the fragility of life. In response to these experiences they learned to *appreciate small things and to live in the moment* (Fisher 1995; Bowling et al. 2003; Gabriel and Bowling 2004; Reichstadt et al. 2007; Kalfoss 2010: Reichstadt et al. 2010; Söderhamn et al. 2013; Sundsli et al. 2013a)

> Although I have problems coping with increasing tiredness, I am appreciative for each day. It is today which makes me happy, the small and large things

> There are so many small things to be happy over, suddenly I am happy because I can do something (Kalfoss 2010)

Other older persons told how they achieved *self-growth by overcoming a crisis* and were finally able to perceive such events as a necessary part of life (Fisher 1995; Söderhamn 1998; Bergland and Narum 2007; Kalfoss 2010; Söderhamn et al. 2013; Sundsli et al. 2013a).

> Both good and bad times teach us something and can be a comfort. This is part of life and part of healthy development. (Kalfoss 2010)

> When I got cancer I thought it through some days. So I was finished with it. I saw on it with a good mood. The more you have gone through, the more it will help for the future. (Söderhamn et al. 2013)

Going through such experiences apparently allowed some of them finding a deeper meaning in life and reaching a state of wisdom and inner integrity as it was described by Erikson (1997) as the final goal of human becoming in the last phase of life.

Older persons who coped by religious practices found *religious comfort* (Borglin et al. 2005; Knestrick and Lohri-Posey 2005; Moore et al. 2006; Dunn and Riley-Doucet 2007; Kalfoss 2010; Söderhamn et al. 2011), which helped to overcome loneliness (Leung et al. 2004) and gave them the feeling of having "a hand to hold" (Dale et al. 2012) and a higher power to lean on in hard times.

> I just knew God was looking after me. I've always felt that, which is a good way to feel. And as I've gotten older and older, you know, it's become even stronger and I have a deep, deep faith in God (Moore et al. 2006)

> When I have prayed, I have received help to find calm in my illness on a day which was good and to be thankful for the day which was not so good. (Kalfoss 2010)

Religion also gave *hope for resurrection* in the face of death and dying and religious older persons expected to experience a new and probably better afterlife (Leung et al. 2004; Borglin et al. 2005; Knestrick and Lohri-Posey 2005).

> I have an anchorage in my Christian faith that one has something to look forward to. I am not afraid of dying, one knows that death will arrive and then it is important to live so to be prepared for it. […] I have had a good life and I look confidently forward to an even better after life (Borglin et al. 2005)

Those who had no religious affiliation claimed that their individual spirituality helped them to find *inner peace and harmony* (Reichstadt et al. 2010). However, spirituality or religious belief could not always overcome negative feelings. Tragic life events such as the death of a spouse could result in *depression* (Gabriel and Bowling 2004). Some older persons told of *doubt and despair* they experienced after losing a beloved person or when they became aware of the possibility of dying.

> I had to watch my son die….It causes you to doubt your faith (Knestrick and Lohri-Posey 2005)

> Where is God in all of this? (Kalfoss 2010)

> Why, why why, must we die…. This is such a beautiful world and I don't want to die.

3.6.4 Influencing Factors

The satisfaction developmental orientations of actions were influenced by the same external circumstances as the other orientations of action. Declining health often triggered a readjustment of development-related orientations of actions. Loss of a spouse was the second reason for a need to find a new balance in one's life.

3.6.5 Behavioural and Attitudinal Reactions

In order to find new hope in the face of adversities, several older persons resorted to *religious practices* such as praying or going to the church (Bowling et al. 2003; Dunn and Riley-Doucet 2007). *Meditation* was also occasionally mentioned as a means to find inner peace and a deeper meaning in life (Dunn and Riley-Doucet 2007). As already indicated above, development-related orientations of action are themselves an attitudinal reaction if older persons fail to meet their body-related, social or identity-related orientations of action. A denial of health problems or care dependency is a manifestation of a denial of adversities that older persons tend to resort to if they cannot meet their desire for physical integrity or self-reliance. The acceptance of physical limitations or losses is an expression of the tendency to downsize expectations and to remain sceptical about future possibilities. Thinking positive as an expression of hope is, on the other hand, an attitudinal reaction that helps to counterbalance this tendency to scepticism. Facing adversities may prepare older persons to deal with them and searching proactively for new perspectives may counterbalance an attachment to the past that can no longer be met because increasing frailty prevents an independent life in one's own home. In sum, development-related orientations of actions are responses to changes in the circumstances of life that require a development of the person.

3.7 Discussion

The descriptions of the older persons confirm the theoretical assumption that quality of life is a multidimensional concept. The qualitative studies, however, yielded more dimensions than the theoretical models discussed in Chap. 1. They provide a picture that is more complete. They add furthermore a new idea to the understanding of quality of life. Whereas the theoretical models assumed that quality of life was composed of dimensions that simply have to be added, the older persons frequently pointed to the fact that there are opposite needs that have to be satisfied in a balanced way in order to achieve real well-being. Although this idea was not explicitly addressed in any of the previously mentioned theories about quality of life, it is not new. The older persons just referred to the doctrine of the golden mean as it was described by Aristotle (1999) in the Nicomachean Ethics. According to this doctrine eudaimonia—the Greek term for happiness— is achieved if people succeed in finding a balance between two extremes, both of which would be a vice if followed without regard to the other. Aristotle provides several examples for such balances between extremes that reflect the cultural values of his own time, for example, the balance between cowardice and foolhardiness that may result in courage. Such a balance is a virtue and requires a stable disposition that must be pursued and maintained with some effort. The older persons seemed to be aware of this idea when they described their efforts to cope with adversities in life. Although they were concerned about other values than the Greek philosopher they had understood the underlying principle of his ethics. Even if most of them were not familiar with his writings their life experience had taught them some wisdom and they intuitively grasped an idea that is deeply rooted in the European culture. In a similar way Chinese older persons who participated in some of the investigated studies (Leung et al. 2004; Kwok and Tsang 2012) may have been influenced by Chinese thought traditions. In Chinese philosophy the duality of Yin and Yang describes how opposite forces are complementary and interdependent and hence need to be balanced in order to achieve harmony in life.

However, no older person gave a complete description of the system of balances as it is shown in Fig. 3.2. They were only partially aware of such balances. Some, for example, mentioned the required balance between activity and rest, others the balance between closeness and distance. Such partial knowledge is due to two reasons. At first, persons never have a complete awareness of their lifeworld. The lifeworld is predominantly taken for granted and remains unreflected (Schütz and Luckmann 1973). Everyday life is based on tacit knowledge. If older persons participate in qualitative studies they have to distance themselves from their lived experience and reflect upon it. As a result they produce islands of reflection that remain surrounded by a sea of tacit assumptions. Furthermore, the doctrine of the golden mean describes an ideal state. Always to find the right balance is a virtue that is difficult to achieve. It requires self-composure that is gained by continuous self-reflection. As everyday life, however, is determined by unreflected habits, older persons were unlikely to completely realize this ideal. For this reason they also reported about instances when they could not satisfy their orientations of action and lost their inner balance. They had acquired this balance through their life experience and it had become their habitual way of life that they maintained rather intuitively. Being confronted with adversities could make them reflect upon their usual way of life and they struggled to regain their inner balance by an inner reorientation. Such self-reflection could result in a higher degree of maturity but due to the imperfect nature of human beings self-awareness and self-composure that older persons gained were not complete.

Unlike the older persons, a researcher is an external observer of their lives. He remains detached from their experiences and struggles. This inner distance allows him to compose a theoretical picture from the details he has been told by the research participants. In this way, statements of the older persons gave hints to the underlying principle according to which the system of balances as presented above was finally constructed. Once the principle was understood it allowed identifying the same interdependence of opposite orientations of action among the other needs that were described in the qualitative studies—even if the older persons were not aware of the existence of such a balance between particular pairs of needs. In this sense, the theoretical model is more complete than the lived experience from which it was derived. One should, however, not forget that the model proposed here is just a reconstruction of this lived experience. As such it is an abstraction of the older person's live that remains necessarily incomplete. Due to the older persons' partial awareness of these orientations one may not preclude that future studies will result in the discovery of further needs that require a rearrangement of the model suggested here.

The metasynthesis that yielded the above-described system of balances has some further limitations. The search for papers investigating quality of life and related terms suffers from a selection bias. Only few studies investigating negative experiences in old age like loneliness were found. If studies focus on positively connoted concepts like successful ageing they are prone to depict a rather positive image of old age for two reasons: Voluntary participation, as required by ethical standards, favours the self-selection of participants, i.e. older persons who experience well-being are more likely to participate than those who do not. As a consequence there were few participants who reported about loneliness and other negative feelings. Furthermore, questions about successful ageing are likely to provoke answers that comply with social norms. Nobody likes to be a looser; hence life experiences tend to be depicted in a rather positive way. Social desirability also seems to be the reason for missing information about older persons' sexuality. Taboos are not likely to be discussed freely when research questions focus on the socially accepted side of life. For the same reason, older persons rarely talked about their self-interests. They rather highlighted their concern for others in order to prevent the impression of being selfish. Such limitations, however, can hardly be avoided when researchers collect verbal data. Each interview is a social interaction where participants perform social roles that are adapted to the expectations of the other side. In fact, such role performance is an essential aspect of everyone's personality. The investigated studies clearly show that closeness and adjustment to social norms are orientations of action that are opposed to unconventionality and privacy. If quality of life is achieved by the balanced satisfaction of these opposite orientations, one may not expect that older persons will reveal every aspect of their life in an interpersonal encounter like an interview. To some extent they will protect their privacy and adjust to social norms in order to accomplish their quality of life. Hence, an essential trait of quality of life seems to be that it is partially hidden to an external observer. As a consequence researchers have to accept that some aspects of the experience of older person remain unspoken.

A further limitation concerns data analysis. Statements of older persons can be ambiguous because they are not used to analyse their lived experience and to distinguish between its various aspects. For this reason their statements cannot always be assigned to a single category. Research findings that summarize such ambiguous verbal data may also be prone to ambiguity. Hence, some interpretations may have been misunderstood in this metasynthesis. However, most findings of the investigated studies were complementary and yielded a coherent picture that the reader may judge for its credibility.

3.8 Conclusion

To summarize, the term quality of life refers to a superordinate concept. It is a subjective state that consists of a balanced satisfaction of opposite orientations of actions in relation to internal capacities and external circumstances. It comprises a multitude of dimensions, which are briefly summarized in Table 3.6.

In practice, it makes little sense to summarize these dimensions under a generic term, such as well-being or life satisfaction, since such terms do not describe any concrete experience. For nurses, caregivers, or social workers who are concerned about older persons' quality of life it is of little value to know that their life satisfaction is low. In order to get practically meaningful ideas about how older persons experience their life they need to know which dimensions of their quality of life have been satisfied and which dimensions have not. Only with such concrete information can they address the needs of older people. They have to do so when they run programs to promote their health or when they care for them in long-term care facilities and during their process of dying. We will turn to these issues in the following chapters.

Table 3.6 Satisfaction of the orientations of action

Body-related orientations of action	
Physical activity Intention to move the body in order to gain fitness and physical strength *Satisfied* when persons enjoy physical activity and gain fitness *Not satisfied* when persons feel that they are losing physical strength	*Physical rest* Intention to reduce physical activity in order to recover and restore physical energies *Satisfied* when people feel that they recover and restore their energy *Not satisfied* when persons feel exhausted and cannot recover
Body protection and regeneration Intention to protect, maintain, and strengthen the integrity of anatomical structures and physiological functions or to restore them in case of damage *Satisfied* when persons do not experience physical harm *Not satisfied* when persons experience damage of anatomical structures or physiological functioning or delayed	*Negligence towards health* Tendency to be careless about the integrity of anatomical structures and physiological functions. Neglect of hygiene, medical check-ups, medical treatment *Satisfied* when persons feel unrestricted by prescriptions to protect, maintain, or restore their health *Not satisfied* when persons feel restrained by the observance of prescriptions to protect, maintain, or restore their health or experience physical discomfort when observing them
Food consumption Desire to have enough and tasty food *Satisfied* when persons feel satiated and enjoy the taste of food *Not satisfied* when persons feel hungry or do not enjoy the taste of food	*Food abstinence* Intention to restrict food consumption to avoid overeating and control body weight *Satisfied* when persons do not feel replete and have normal body weight *Not satisfied* when persons feel replete or are disgusted of fatty dishes or if they become overweight
Sexual desire Desire for intimate contacts and sexual pleasure *Satisfied* when persons experience sexual pleasure *Not satisfied* when persons feel sexually frustrated	*Sexual abstinence* Tendency to avoid intimate contacts and to protect the intimate sphere against intrusion *Satisfied* when persons do not experience undesired sexual contact *Not satisfied* when persons feel sexually harassed
Social orientations of action	
Self-reliance Intention to maintain self-care, to rely on own abilities in order to have no need to get help from others, and to feel responsible for the own health *Satisfied* when persons feel that they are able to care for themselves and do not need the help from others *Not satisfied* when persons lose the feeling of being able to care for themselves and their sense of self-efficacy	*Being cared for* Desire to receive care and support from others and to expect that they will secure the satisfaction of the older person's need *Satisfied* when persons feel that they can rely on others to secure the satisfaction of their needs *Not satisfied* when persons feel neglected by others and lack the feeling that others will secure the satisfaction of their needs

Table 3.6 (continued)

Exerting influence on others Desire to impose at least to some extent one's will on others by demanding that they behave according to one's own expectations or by controlling them in situations when receiving care *Satisfied* when others behave according to the person's expectations or when the person maintains control while receiving care *Not satisfied* when persons feel that they lack control and are controlled by others (for example, by having to wait until getting help or by having to adapt to the expectations of others)	*Attention to the needs of others* Intention to refrain from demands on others in order to avoid becoming an undue burden on them *Satisfied* when persons feel that they do not bother others with their demands and needs *Not satisfied* when persons feel to be a burden on others
Unconventionality Desire to life unrestrained from social norms and rules and tendency to disregard them *Satisfied* when persons feel unrestrained from social norms and rules and enjoy their freedom *Not satisfied* when persons feel restricted by social norms and lack a sense of freedom	*Social adjustment* Intention to observe social norms regarding one's behaviour and appearance and to be compliant with expectations of others *Satisfied* when persons feel that they conform to social norms and rules *Not satisfied* when people feel guilty or ashamed for breaking social norms or rules
Closeness Desire for social contacts, to feel connected with others and to get their attention and emotional support *Satisfied* when persons gain or maintain social contacts and get attention and emotional support from others *Not satisfied* when persons feel lonely and miss beloved ones	*Distance* Desire to protect one's privacy, to withdraw from others, and to be alone *Satisfied* when persons feel that they can withdraw from others and protect their privacy *Not satisfied* when persons feel that others disturb their privacy and that they are exposed to their attention
Identity-related orientations of action	
Work Desire to be busy and productive in order to achieve something *Satisfied* when persons feel busy and enjoy the results of their activities *Not satisfied* when persons feel inactive and unproductive	*Relaxation* Desire to recover from stress and to relax in a comforting environment *Satisfied* when persons recover from stress and find inner calmness *Not satisfied* when persons feel stressed and cannot get relief from burdensome activities
Reflection Tendency to avoid simple amusement and to reflect the experiences of life *Satisfied* when older persons find intellectual satisfaction *Not satisfied* when older persons experience activities as silly and trivial	*Diversion* Desire to get entertainment and distraction to experience joy and fun *Satisfied* when older persons have fun and feel entertained *Not satisfied* when older persons lack entertainment

(continued)

Table 3.6 (continued)

Self-centredness Egoism. Tendency to focus on own needs while ignoring the needs of others *Satisfied* when persons can meet their selfishness *Not satisfied* when concern for others becomes a burden and persons suffer from self-neglect	*Concern for others* Altruism. Finding meaning in life through caring and doing something for others *Satisfied* if persons feel to be useful for others *Not satisfied* if persons feel to be of no use for others
Self-presentation Desire to get attention, acknowledgement, and respect from others *Satisfied* when persons feel respected by others and treated as a valuable member of the society *Not satisfied* when persons feel that others disrespect, stigmatize, or ignore them	*Self-concealment* Tendency to stay in the background and to conceal parts of the self *Satisfied* when persons can hide aspects of their self they do not want to be perceived by others *Not satisfied* when aspects of the self are unintentionally exposed to the attention of others
Positive self-perception Desire for a positive self-image by meeting internal standards, achieving self-imposed goals, or cultivating positive memories *Satisfied* when persons have a positive idea about themselves, achieve self-imposed goals, or enjoy positive memories *Not satisfied* when persons believe to have no value, do not meet inner standards, or suffer from negative memories	*Critical self-perception* Tendency to a critical self-examination and to be aware of one's weakness *Satisfied* when persons have a realistic idea about themselves *Not satisfied* when persons are attached to an illusionary self
Development-related orientations of action	
Attachment to the past Tendency to follow routines, to remain in the familiar place of living, and to cultivate memories *Satisfied* when persons feel that they can continue their usual way of life *Not satisfied* when persons feel disturbed in maintaining their old habits, miss them completely, or feel that they have lost their familiar world	*Searching new perspectives* Tendency to discover new things, to learn new skills, or to change at least parts of habits and life *Satisfied* when persons discover new possibilities and acquire new skills *Not satisfied* when persons feel that life is stagnating
Denial of adversities Tendency to avoid thinking about threats or to deny adversities (e.g. loss of a spouse, a serious disease, prospect of the own death) *Satisfied* when persons can avoid unnecessary worries *Not satisfied* when persons are suddenly overcome by a fear of death or when they feel overwhelmed by problems	*Facing adversities* Tendency to be aware of adversities and to manage them by planning ahead *Satisfied* when persons are aware of and feel prepared to deal with negative events and threats *Not satisfied* if persons feel deceived by wrong promises from others

Table 3.6 (continued)

Scepticism Tendency to be realistic and to downsize expectations *Satisfied* when persons gain equanimity and get detached from their losses *Not satisfied* if people get attached to unrealistic hope	*Hope* Tendency to overcome adversities by finding something positive in the negative *Satisfied* when persons experience self-growth by overcoming crises or find hope in resurrection *Not satisfied* when persons suffer from despair or from doubts about a deeper meaning of life

References

Andersson M, Hallberg IR, Edberg A-K (2008) Old people receiving municipal care, their experiences of what constitutes a good life in the last phase of life: a qualitative study. Int J Nurs Stud 45(6):818–828

Aristotle (1999) Nicomachean ethics. Translated by W.D. Ross. Batoche Books, Kitchener

Bauger L, Bongaardt R (2016) The lived experience of well-being in retirement. Int J Qual Stud Health Well Being 11(1):33110. https://doi.org/10.3402/qhw.v11.33110

Bergland A, Narum I (2007) Quality of life demands comprehension and further exploration. J Aging Health 19(1):39–61

Boggatz T (2013) Leisure activities among older Germans - a qualitative study. Int J Older People Nursing 8(2):174–185

Boggatz T (2019) Betreutes Wohnen. Perspektiven zur Lebensgestaltung bei Bewohnern und Betreuungspersonal. Springer, Heidelberg

Borglin G, Edberg A-K, Rahm Hallberg I (2005) The experience of quality of life among older people. J Aging Stud 19(2):201–220

Bowling A, Gabriel Z, Dykes J, Dowding LM, Fleissig A, Banister D, Sutton S (2003) Let's ask them: a national survey of definitions of quality of life and it's enhancement among people aged 65 and over. Int J Aging Hum Dev 56(4):269–306

Bryant T, Brown I, Cogan T, Dallaire C, Laforest S, McGowan P, Raphael D, Richard L, Thompson L, Young J (2004) What do Canadian seniors say supports their quality of life? Findings from a national participatory research study. Can J Public Health 95(4):299–303

Dale B, Söderhamn U, Söderhamn O (2012) Life situation and identity among single older home-living people: a phenomenological–hermeneutic study. Int J Qual Stud Health Well Being 7. https://doi.org/10.3402/qhw.v7i0.18456

Dunn KS, Riley-Doucet CK (2007) Self-care activities captured through discussion among community-dwelling older adults. J Holist Nurs 25(3):160–169

Erikson EH (1997) The life cycle completed. W.W. Norton & Company Inc, New York

Farquhar M (1995) Elderly people's definitions of quality of life. Soc Sci Med 41(10):1439–1446

Fisher BJ (1995) Successful aging, life satisfaction, and generativity in later life. Int J Aging Hum Dev 41(3):239–250

Gabriel Z, Bowling A (2004) Quality of life from the perspectives of older people. Ageing Soc 24(5):675–691

Green S, Sixsmith J, Ivanoff S, Sixsmith A (2005) Influence of occupation and home environment on the wellbeing of European elders. Int J Ther Rehabil 12(11):505–509

Gustafsson K, Sidenvall B (2002) Food-related health perceptions and food habits among older women. J Adv Nurs 39(2):164–173

Haak M, Fänge A, Iwarsson S, Ivanoff S (2007) Home as a signification of independence and autonomy: experiences among very old Swedish people. Scand J Occup Ther 14(1):16–24

Hambleton P, Keeling S, McKenzie M (2008) Quality of life is…: the views of older recipients of low-level home support. Soc Policy J N Z 33:146–162

Heidegger M (1962) Being and time. HarperCollins, New York

Infantino M (2004) Gardening: a strategy for health promotion in older women. J N Y State Nurses Assoc 35(2):10–17

Kalfoss M (2010) Quality of life among Norwegian older adults: focus group results. Res Gerontol Nurs 3(2):100–112

Knestrick J, Lohri-Posey B (2005) Spirituality and health: perceptions of older women in a rural senior high rise. J Gerontol Nurs 31(10):44–50

Kwok JYC, Tsang KKM (2012) Getting old with a good life: research on the everyday life patterns of active older people. Ageing Int 37:300–317

Larson A, Haglund L, Hagberg JE (2009) Doing everyday life - experiences of the oldest old. Scand J Occup Ther 16:99–109

Lette M, Stoop A, Lemmens LC, Buist Y, Baan CA, de Bruin SR (2017) Improving early detection initiatives: a qualitative study exploring perspectives of older people and professionals. BMC Geriatr 17(1):132–145

Leung K-K, Wu E-C, Lue B-H, Tang L-Y (2004) The use of focus groups in evaluating quality of life components among elderly Chinese people. Qual Life Res 13(1):179–190

Maslow AH (1943) A theory of human motivation. Psychol Rev 50:370–396

Mayring P. (2003). Qualitative Inhaltsanalyse 8. Aufl. [Qualitative Content Analysis 8th ed.] Weinheim: Beltz

Mead GH (1967) Mind, self, and society from the standpoint of a social behaviorist. The University of Chicago Press, Chicago

Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009) Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. PLoS Med 6(7):e1000097

Moore SL, Metcalf B, Schow E (2006) The quest for meaning in aging. Geriatr Nurs 27(5):293–299

Musselwhite C, Haddad H (2010) Mobility, accessibility and quality of later life. Qual Ageing Older Adults 11(1):25–37

Pettigrew S, Roberts M (2008) Addressing loneliness in later life. Aging Ment Health 12(3):302–309

Reichstadt J, Depp CA, Palimkas LA, Folsom DP, Jeste DV (2007) Building blocks successful ageing: a focus group study of older adults' perceived contributors to successful aging. Am J Geriatr Psychiatr 15(3):194–201

Reichstadt J, Sengupta G, Depp CA, Palimkas LA, Jeste DV (2010) Elders perspective successful aging: qualitative interviews. Am J Geriatr Psychiatr 18(7):567–575

Rudman DL, Durdle M (2009) Living with fear: the lived experience of community mobility among older adults with low vision. J Aging Phys Act 17(1):106–122

Schütz A, Luckmann T (1973) The structures of the life-world. Northwestern University Press, Evanston

Shearer N, Fleury J (2006) Social support promoting health in older women. J Women Aging 18(4):3–17

Shrestha S, Zarit SH (2012) Cultural and contextual analysis of quality of life among older Nepali women. J Cross Cult Gerontol 27(2):163–182

Smith JM (2012) Toward a better understanding of loneliness in community-dwelling older adults. J Psychol 146(3):293–311

Söderhamn O (1998) Self-care ability in a group of elderly Swedish people: a phenomenological study. J Adv Nurs 28(4):754–753

Söderhamn U, Dale B, Söderhamn O (2011) Narrated lived experiences of self-care and health among rural-living older persons with a strong sense of coherence. Psychol Res Behav Manag 4:151–158

Söderhamn U, Dale B, Söderhamn O (2013) The meaning of actualization of self-care resources among a group of older home-dwelling people—a hermeneutic study. Int J Qual Stud Health Well Being 8:1–9

Stephens C, Breheny M, Mansvelt J (2015) Healthy ageing from the perspective of older people: a capability approach to resilience. Psychol Health 30(6):715–731

Stjernborg V (2017) The meaning of social participation for daily mobility in later life: an ethnographic case study of a senior project in a Swedish urban neighbourhood. Ageing Int 42:374–391

Sundsli K, Espnes GA, Söderhamn O (2013a) Being old and living alone in urban areas: the meaning of self-care and health on the perception of life situation and identity. Psychol Res Behav Manag 6:21–27

Sundsli K, Espnes GA, Söderhamn O (2013b) Lived experiences of self-care among older physically active urban-living individuals. Clin Interv Aging 8:123–130

Tarzia L, Bauer M, Fetherstonhaugh D, Nay R (2013) Interviewing older people in residential aged care about sexuality: difficulties and challenges. Sex Disabil 31(4):361–371

Wicks A (2006) Older women's 'ways of doing': strategies for successful ageing. Ageing Int 31(4):263–275

Wilhelmson K, Anderson C, Waern M, Allebeck PR (2005) Elderly people's perspectives on quality of life. Ageing Soc 25(04):585–600

Health Promotion and Quality of Life in Old Age

4

4.1 Health Promotion

With the world population growing older age-related diseases are on the rise. They are a consequence of the demographic transition. Several scenarios based on varying assumptions attempt to predict the future direction of this development (Nusselder 2003). According to the “expansion of morbidity” theory, increasing life expectation will result directly in an increase of morbidity. In contrast, the “compression of morbidity” theory assumes that the spread of healthy lifestyles among the older population will result in a delayed onset of frailty and hence reduce every person’s life span of suffering from age-related diseases. Although there is no evidence for either theory, the latter scenario is obviously more desirable. To achieve this goal health promotion and disease prevention seem to be advisable.

The idea of health promotion began to spread since the publication of the Ottawa Charter for health promotion (WHO 1986). According to the Ottawa Charter “health promotion is the process of enabling people to increase control over, and to improve, their health”. Health promotion includes a wide range of social and environmental interventions that are designed to benefit and protect individual people’s health and quality of life by addressing and preventing the root causes of ill health. As such, it goes beyond health care and seeks to build a healthy public policy, to create supportive environments, to strengthen public participation, and to encourage the development of personal skills that enable persons to make decisions conducive to health and to deal with illness. In this context, health education that aims to encourage a healthy lifestyle and to change unhealthy behaviour is just one element.

Health promotion is meant to complement disease prevention that seeks to avoid the manifestation of particular diseases. Disease prevention is commonly divided into primary prevention which aims to prevent disease before it occurs (for example by vaccinations or by provision of information on behavioural and medical health risks), secondary prevention which aims to detect and treat diseases as early as possible in order to reduce their impact (for example by regular medical check-ups or diet and exercise programs in the context of treatment), and tertiary prevention which aims to soften the impact of an

T. Boggatz, *Quality of Life and Person-Centered Care for Older People*,
https://doi.org/10.1007/978-3-030-29990-3_4

illness with lasting effects in order to improve functional capacities, quality of life, and life expectancy (for example by chronic disease management programs or through support groups that allow members to share strategies for living well).

Disease prevention is often said to define health in a negative way as the absence of disease, and to focus on efforts for risk-groups with the intention of bringing people back to "normal life" (Seedhouse 1997). Health promotion, on the other hand, is described as a "holistic" approach as it takes the individual and her context into account and aims to address the social and economic determinants of ill health (MacDonald 1998). In contrast to disease prevention, health promotion strategies have a wider scope. They do not primarily target specific causes of ill health; they rather aim for an increased health, well-being, and resistance to disease. Although conceptually distinct, in practice interventions of health promotion and disease prevention are often similar (Tengland 2010) and for reasons of brevity, we will refer in this chapter to both types of intervention as health promotion. Both try to change environmental factors and individuals' beliefs and attitudes through increasing opportunities or raising awareness. Promoting physical exercises, diet, reduced consumption of alcohol, or community ties is useful to strengthen health, to reduce risks for diseases, and even to avoid complications or recurrences in case of disease. In fact, since many older people are no longer in a state free of disease promoting their health becomes equal to secondary or tertiary prevention. Finally, the ultimate goal of preventing specific diseases and promoting basic health is manifest health, which is—as we have seen in the previous chapter—an integral part of quality of life. At a first glance, it seems therefore reasonable to assume that health promotion and disease prevention will increase older persons' quality of life.

When it comes to concrete interventions, a variety of strategies to promote health and to prevent diseases of older persons can be found in the literature: Health advertisements in the media, health brochures, health advices from general practitioners or community nurses, home visits, courses for health education, exercise groups, where older people can practice together, peer mentorship for individual activities, and of course combinations of two or more of these interventions. These interventions may have a broad focus on health promotion in general or a narrow focus on the prevention of a particular health problem like falls or bone fractures among older persons with osteoporosis. In the first case, there is a heterogeneous target group with a variety of interests and it may be difficult to design a program that fits everybody's needs. In the second case, the target group is more homogeneous, but the program will exclude all those who are not perceived to be at risk.

All interventions mentioned above have in common that they represent just one element of health promotion in its proper sense. They are not so much concerned about creating supportive environments or strengthening community action, they rather focus on the development of personal skills. Since they aim at changing the behaviour of older persons, they intend to interfere more or less in their lives. If older persons do not behave in a recommended way, health experts often interpret this as a lack of knowledge and information that has to be eliminated. For example, a cross-sectional, nationally-representative health surveys in England found that few of the 561 respondents knew the recommended physical activity target, but more than one half believed they had enough physical activity in their daily life (Chaudury and

Nicola Shelton 2010). Such divergence from recommended norms, however, may not be due to a lack of knowledge but due to different conceptualizations of healthy ageing (Hung et al. 2010). Whereas academic experts focus on the maintenance of physical functioning, older persons perceive health in the broader context of quality of life which encompasses social, identity related and developmental dimensions. Hence, at a second glance there is no straightforward relationship between health promotion and quality of life. As a consequence, health promotion as designed by experts may interfere with older persons' habitual balance between opposite orientations of action. This interference may be welcome if it empowers older persons to satisfy their own needs, but it may also be disturbing, if it is implemented in a paternalistic top-down approach and gets into conflict with other dimensions of quality of life that are of greater importance for them. In order to promote health and to prevent diseases in a person-centred way one has to understand the various ways how these kinds of interventions may support or interfere with their orientations of action.

To do so, this chapter will summarize the findings of 49 qualitative studies about older persons' ideas about health promotions and their experiences with health promoting interventions. The studies were identified by a literature research in the databases Pubmed, CINAHL, and Embase as shown in Fig. 4.1. The research was restricted to studies published in either English or German that were not older than 20 years.

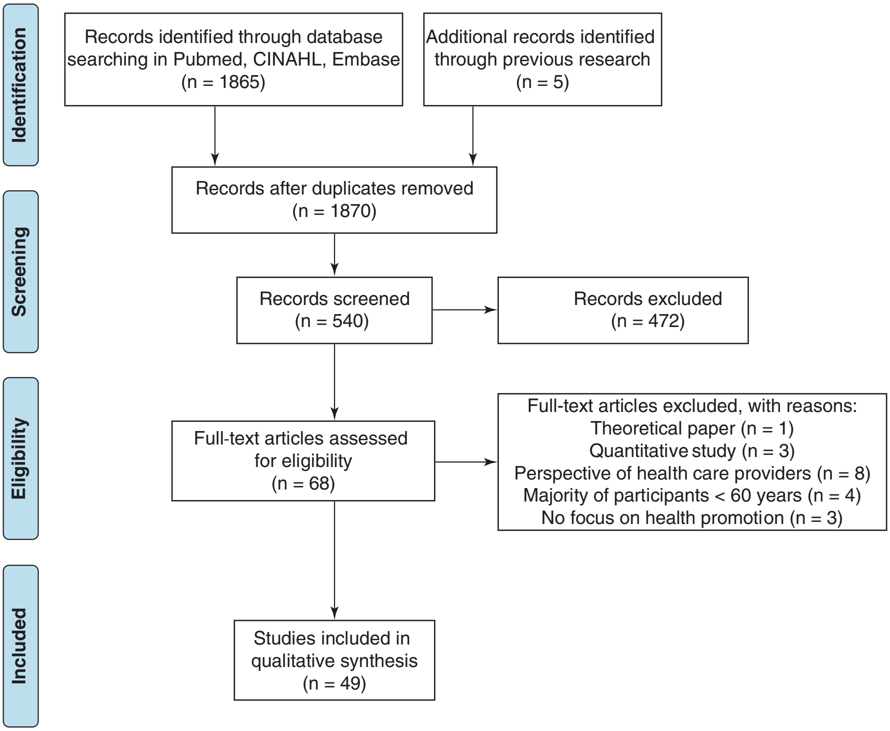

Fig. 4.1 Search strategy according to PRISMA (Moher et al. 2009)

Studies were included if they had a qualitative design and investigated how older persons understood health promotion in general or how they experienced a particular health promoting or disease preventing intervention as participants. The majority of study participants had to be above 60 years so that the results reflected the perspective of the older population. Studies that also described the perspective of health care providers were only included, if the perspective of older persons was depicted separately. Five studies presented in the previous chapter about quality of life among community-dwelling older persons were also included because a part of their results had a direct focus on health promoting activities (Söderhamn 1998; Gustafsson and Sidenvall 2002; Shearer and Fleury 2006; Söderhamn et al. 2011, 2013).

Table 4.1 provides an overview over the countries and the focus of interest of the investigated studies. Altogether 49 studies met the inclusion criteria. The majority of

Table 4.1 Investigated studies by country and focus

	Number of studies
Studies by country	
Europe	*26*
Denmark	1
Norway	1
Sweden	8
Sweden and Ireland	1
Ireland	1
United Kingdom	9
Netherlands	1
Germany	2
Austria	1
Italy	1
America	*19*
USA	17
Canada	2
Asia and the Pacific	*4*
New Zealand	1
Taiwan	1
China	1
Japan	1
Studies by focus	
Perspective of older persons regardless of participation in health-related programs on	*24*
Health promotion in general	15
Fall prevention	4
Mental health	1
Diet	1
Information Seeking	1
Health messages in the media	2
Perspective of participants in/ users of	*25*
Physical exercise program	19
Fall prevention program	2
Health awareness program	2
Complementary health	2

these studies have been carried out in Europe (mainly in the UK and Sweden), followed by America (mainly in the USA). Studies from Australia, New Zealand, and Asia were rather rare. 24 studies investigated ideas about and attitudes towards health promotion and disease prevention regardless of whether older persons participated in health-related programs or not. They provided insight into the perspective of both users and non-users. 15 of these studies had a broad focus and were concerned about health promotion in general; four studies concentrated on the issue of fall prevention; one study focused on ideas regarding mental health, one study on ideas about diet, one study on information seeking strategies regarding health, and two studies on older persons' perceptions of health messages spread in the media. The remaining 25 studies were restricted to users of particular interventions and explored their respective experiences. In 19 of these studies the intervention consisted of a program to promote physical activity and exercise (one of them using peer mentorship to encourage exercising at home), in two studies of exercises with a particular focus on fall prevention, in two further studies of a health awareness program that aimed to increase health-related knowledge and competencies among older immigrants, and finally in two studies of complementary health care that was used by a particular group of older persons. Table 4.2 shows the investigated studies sorted by authors and details their places, focus of interest, participants, and methods. The findings were analysed and synthesized by using the same method as described in Chap. 2.

4.2 Health Promotion and Body-Related Orientations of Action

As expected, health promotion was supported by, but also interfered with body-related orientations of action—except orientations related to sexuality which did not play a role in the context of health promotion. Older persons practiced health-related activities according to their individual balance between physical activity and physical rest, body protection and negligence towards health, as well as food consumption and food abstinence. This balance depended on their physical condition. Internal resources like health-related knowledge and external circumstances also had some influence. Health-related activities were behavioural reactions to perceived threats or unmet needs of body-related orientations of action. They were associated with underlying attitudinal reactions that either reinforced the unsatisfied need or attempted to compensate it by an inner reorientation towards other needs. The aspects of each orientation of action, the different kinds and degrees of their satisfaction, their influencing factors, and the behavioural and attitudinal reactions of the older persons are shown in Table 4.3. As in the previous chapter, they are printed in bold italics in the running text.

4.2.1 Physical Activity Versus Physical Rest

When older persons were asked about their attitudes regarding physical activity, they were concerned about finding a balance between physical activity and physical rest. But there were also some older persons who had a rather one-sided tendency to either activity or rest and could therefore lose a healthy balance between both.

Table 4.2 Investigated studies by authors

Author(s)	Country	Focus on…	Research question	Inclusion criteria	Number of participants	Data collection by	Research tradition
Barenfeld et al. (2015)	Sweden	Health Awareness Program	To explore the experiences of a health promotion program among immigrants ageing in Sweden	Older immigrants >70 years	14	Interviews	Grounded theory
Barenfeld et al. (2017)	Sweden	Health Awareness Program	To explore the use of health promoting messages amongst older immigrants 6 to 12 months after participation in a health promotion program	Older immigrants >70 years	12	Interviews	Grounded theory
Belza et al. (2004)	USA	Exercise/ physical activity	To identify barriers and facilitators to engaging in physical activity and to better understand culturally appropriate physical activity and exercise programs	Older immigrants 52–85 years	71	Focus groups	n.s.
Berlin Hallrup et al. (2009)	Sweden	Fall prevention	To explore the lived experience of fall risk from a lifeworld perspective in elderly women with previous fragility fractures	Older women 76–86 years	13	Interviews	Phenomenology
Berry et al. (2009)	Canada	Health messages	What were the positive and negative aspects of health advertisements, the perceived credibility of the source of the advertisements, and the usefulness of promoting a website?	Older persons 55–80 years	29	Focus groups	n.s.[a]
Bethancourt et al. (2014)	USA	Exercise/ Physical activity	To better understand the barriers and facilitators of PA and participation in PA programs among older adults	Older persons 66–78 years	52	Focus groups	n.s.

Boggatz and Meinhart (2017)	Austria	Health in general	To identify different types of attitudes towards health promotion among older adults	Older persons >60	36	Interviews	Hermeneutics
Boggatz (2011)	Germany	Health in general	To identify different types of attitudes towards health promotion among older adults	Older persons 50–83 years	31	Interviews	Hermeneutics
Brännström et al. (2013)	Sweden	Fall prevention	The lived experience of living in an ageing body and using a walker in daily life.	Older persons 79–95	7	Interviews	Hermeneutic Phenomenology
Bredland et al. (2018)	Norway	Exercise/ physical activity	Challenges and motivators encountered by retired men in maintaining physical activity when ageing	Older men 66–83 years	9	Focus groups and diaries	n.s.
Cartwright (2007)	UK	Complementary health care	The experiences of older people using subsidized complementary health care	Older persons 63–84 years	17	Interviews	Interpretative Phenomenology
Collins et al. (2004)	USA	Health in general	To describe definitions of health in Hispanic and African American elders	Older Hispanics or Africans 65–92 years	45	Interviews	n.s.
Costello et al. (2011)	USA	Exercise/ physical activity	The motivators, barriers, and beliefs regarding physical activity of independent-living older adults with easy access to fitness facilities	Older person >60 years	31	Focus groups	n.s.
Dickinson et al. (2011)	UK	Fall prevention	Older people's perceptions of the facilitators and barriers to participation in fall prevention interventions	Older persons (British, South Asian, Chinese) 60–95 years	65 122	Interviews Focus groups	Grounded theory

(continued)

Table 4.2 (continued)

Author(s)	Country	Focus on…	Research question	Inclusion criteria	Number of participants	Data collection by	Research tradition
Frenn (1996)	USA	Health in general	How older adults promote their health, what influences these effort, what aspects of the environment are relevant for health promotion	Older person 62–88 years	80 31	Participant observation Interviews	Grounded theory
Gilbert et al. (2012)	USA	Health in general	To discover perceptions of facilitators and barriers to healthy ageing	Older persons 80–95 years	10	Interviews	Phenomenology
Graham and Connelly (2013)	Canada	Exercise/ physical activity	To understand rural community-dwelling older adult participants' shared values, beliefs, and behaviours related to exercise as self-care	Older persons >65 years	17	Interviews and participant observation	Ethnography
Grasser and Craft (2000)	USA	Health in general	What self-health care practices do participants identify as important to their well-being?	Older persons 60–85 years	20	Interviews	n.s.
Gustafsson and Sidenvall (2002)	Sweden	Diet	Food-related health perceptions and food habits among older women	Older women >65 years	18	Interviews	Ethnography
Hardy and Grogan (2009)	UK	Exercise/ physical activity	To gain an understanding of personal and social influences on physical activity	Older persons 52–87 years	48	Interviews	Grounded Theory
Horne et al. (2010)	UK	Exercise/ physical activity	To explore the influence of primary health care professionals in increasing exercise and physical activity among older community dwellers	Older persons (White and South Asian) 60–70-years	40 87	Interviews Focus groups	Ethnography

Horne et al. (2013)	UK	Exercise/ physical activity	To explore the barriers for initiating and maintaining regular physical activity among UK Indian, Pakistani, and White British adults in their 60s	Older persons (White and South Asian) 60–70-years	57 116	Interviews Focus groups	Naturalistic Inquiry
Hutton et al. (2000)	New Zealand	Exercise/fall prevention	Perceptions that older adults at risk at falls, and previously involved in organized group exercise, have physical activity	Older persons 68–81 years	20	Focus groups	n.s.
Janssen and Stube (2014)	USA	Exercise/ physical activity	To explore older adults' perceptions of participation in physical activity	Older persons >65 years	15	Interviews and observation	Phenomenology
Komatsu et al. 2017	Japan	Exercise/ physical activity	To understand older persons' perceptions of the physical, mental, and social changes they underwent as a result of the physical activity.	Older persons 66–86 years	26	Focus groups	n.s.
Leavy and Aberg (2010)	Sweden and Ireland	Exercise/ physical activity	To explore perceptions of physical activity held by older adults	Older persons >65 years	30	Interviews	n.s.
Lees et al. (2005)	USA	Exercise/ physical activity	To determine barriers to the exercise behaviour of older adults	Older persons >65 years	66	Focus groups	n.s.
Lette et al. (2017)	Nether-lands	Health in general	To gain insight in older persons' perspectives on health and living environment in relation to living independently at home, to identify their needs and preferences for initiating and receiving care and support	Older persons >55 years[b]	36	Interviews	n.s.

(continued)

Table 4.2 (continued)

Author(s)	Country	Focus on…	Research question	Inclusion criteria	Number of participants	Data collection by	Research tradition
Li et al. (2013)	China	Exercise/ physical activity	To explore the experiences and perceptions of the elderly community regarding physical activity	Older persons 63–73 years	12	Interviews	Phenomenology
Lorenc et al. (2012)	UK	Complementary health care	To explore older peoples' decision making regarding complementary and alternative medicine use and their perceptions and experiences of well-being	Older persons >61 years	37	Focus groups	n.s.
Maddox (1999)	USA	Health in general	The meaning older women give to health and health behaviours the currently are or previously were engaged in	Older women >55 years	25	Interviews	Phenomenology
Mathews et al. (2010)	USA	Mental health	To identify perceived PA enablers and barriers described by focus group participants in the context of cognitive health	Ethnically diverse older person 50–90 years	396	Focus groups	n.s.
McGrath et al. (2016)	Ireland	Information seeking	To explore the strategies used by older people to obtain information about community health and social services	Older persons 62–85 years	17	Focus groups	n.s.
Menichetti and Graffigna (2016)	Italy	Health in general	Older people's experiences and subjective meanings concerning their engagement in health promotion and the emotional and pragmatic difficulties they face during their engagement	Older persons 65–75 years	25	Interviews and Q-sorting task	Ethnoscience

Miller and Iris (2002)	USA	Exercise/ physical activity	To describe older adults’ attitudes and beliefs regarding wellness, self-care, and participation in health promotion activities	Older persons 62–91 years	45	Focus groups	n.s.
Miller (2010)	USA	Fall prevention	To gain an understanding of older peoples’ experiences and perceptions of education about fall prevention	Older persons 69–98 years	10	Interviews	Hermeneutic phenomenology
Morris Docker (2006)	UK	Exercise/fall prevention	To identify factors that influence the attraction of Tai Chi for older people	Older persons 52–71 years	7	Interviews and observation	Ethnography
Nielsen et al. (2014)	Denmark	Exercise/ physical activity	To explore how and why participants in structured exercise intervention programs continue or stop exercising after the program is finished	Older persons 39–71 years[c]	28	Focus groups	n.s.
Patzelt et al. (2016)	Germany	Health Messages	How older men and women would prefer to be addressed for health and prevention programs	Older persons >65 years	42 12	Focus groups Subsequent interviews	n.s.
Price et al. (2011)	USA	Exercise/ physical activity	Older adults’ perceptions of physical activity and cognitive health	Older persons (black and white) 65–74 years	55	Focus groups	n.s.
Resnick et al. (2006)	USA	Exercise/ physical activity	To explore the experience of an exercise self-efficacy and to establish what helped to engage in exercise and what decreased willingness to exercise	Older persons (black minority) >62 years	148	Focus groups	Naturalistic inquiry
Shearer and Fleury (2006)	USA	Health in general	To describe the types and processes of social support for health promotion in older women.	Older women 55–93 years	51	Focus groups	n.s.

(continued)

Table 4.2 (continued)

Author(s)	Country	Focus on…	Research question	Inclusion criteria	Number of participants	Data collection by	Research tradition
Simmonds et al. (2016)	UK	Exercise/ physical activity	To explore the acceptability of high-impact physical activity for increasing bone strength in later life	Older persons 65–88 years	31	Interviews	n.s.
Söderhamn (1998)	Sweden	Health in general	To describe self-care ability in a group of Swedish elderly, to elucidate the meaning of actualizing this self-care ability into self-care activity	Older persons 65–90 years	54	Written statements of participants	Phenomenology
Söderhamn et al. (2011)	Sweden	Health in general	To describe the lived experiences of self-care and features that may influence health and self-care among older persons with a strong sense of coherence	Older persons 67–89 years	11	Interviews	Descriptive phenomenology
Söderhamn et al. (2013)	Sweden	Health in general	To investigate the meaning of the actualization of self-care resources[d]	Older persons 67–89 years	11	Interviews	Hermeneutic phenomenology
Stevens et al. (2015)	UK	Peer mentoring	How peer mentors in a home based exercise program experienced their role.	Older persons volunteering as peer mentors 52–84 years	10	Interviews	n.s.
van Leuven 2010	USA	Health in general	Beliefs, values, and lifestyles of older persons who self-identified as healthy in contrast to those who self-identified as less healthy	Older persons >75 years	18	Interviews	n.s.
Wang et al. (2001)	Taiwan	Health in general	To explore perceptions of health promoting self-care in community-dwelling older adults	Older persons 67–83 years	22	Focus groups	n.s.

n.s. not specified

[a] Qualitative research in a mixed method study

[b] Study included also health professionals but their perspective is not reported here

[c] 2 groups with men >60 years, 1 group with men <60 years

[d] Reanalysis of data from Söderhamn et al. (2011)

4.2.1.1 Physical Activity

For some older persons physical activity was *restricted to the performance of daily routines* (Hutton et al. 2000: Boggatz 2011; Graham and Connelly 2013; Horne et al. 2013; Simmonds et al. 2016; Bredland et al. 2018). Self-care, housework, and shopping were considered to be sufficient for a healthy level of activity.

> Do I need to do more exercise? This is what I ask myself… I do all the housework every day. (Horne et al. 2013)

> I think getting up off of the couch is exercise … any movement at all is exercise. (Graham and Connelly 2013)

Some of these older persons explained that daily routines were strenuous enough for their age leaving no energy for exercise (Bredland et al. 2018). Others expected *no benefit from additional exercise* for health (Leavy and Aberg 2010; Mathews et al. 2010; Boggatz 2011; Costello et al. 2011; Horne et al. 2013; Boggatz and Meinhart 2017). Some were convinced that they were too old to improve their health, and others claimed that health was just a result of good luck or of taking medication. In any case, efforts spent in exercising were perceived as rather futile.

Other older persons, however, had an explicit *desire for physical activity* (Hutton et al. 2000; Leavy and Aberg 2010; Söderhamn et al. 2011; Söderhamn et al. 2013). According to their opinion, physical activity should not be restricted to daily routines.

> I think another thing too is … to use your body as a whole kind of thing, rather than just… walking around the house etcetera, you are active but you may not be using all the other parts of your body that need exercise. (Hutton et al. 2000)

Their ideas about exercises corresponded with the aims of physical activity promotion. By performing physical activities they expected to meet their *desire for mobility and physical fitness*. They wanted to maintain the flexibility of their joints and to improve their physical strength in order to endure desired efforts (Miller and Iris 2002; Belza et al. 2004; Hardy and Grogan 2009; Costello et al. 2011; Graham and Connelly 2013; Bethancourt et al. 2014; Patzelt et al. 2016; Boggatz and Meinhart 2017; Lette et al. 2017). Such immediate benefits were also expected to occur in case of existing health problems. Here, physical activity took the character of secondary or even tertiary prevention.

> The main reason I started at the fitness centre was because I had a knee replacement…, but I have to keep my knee, you know healthy and exercise. (Costello et al. 2011)

Beside such immediate mobility-related effects physical activity was motivated by *expectations of further health benefits*. For some older persons these benefits were rather unspecific and consisted of vitality, longevity, and the prevention of diseases (Belza et al. 2004; Hardy and Grogan 2009; Costello et al. 2011; Li et al. 2013). Others, however, had concrete ideas and mentioned weight loss (Belza et al. 2004;

Table 4.3 Body-related orientations of action, influencing factors, behavioural and attitudinal reactions

Orientations of action and their satisfaction	
Physical activity	Restricted to performance of daily routines
	No benefit from additional exercise expected
	Desire for physical activity
	Desire for mobility and physical fitness
	Expectations of further health benefits
	Need for age appropriate exercise
	Desire to get rid of energy
	Going to the limits
Satisfaction of physical activity	Enjoyment of moving the body
	Gain of energy
	Improved mobility
	Getting tired after exercise improved sleep
	Restlessness due to excessive energy
Physical Rest	Balancing activity with rest
	Desire for comfort and inertia
Satisfaction of physical rest	Recovery from efforts
	Physical relief with assistive devices
	Overstrain
Body protection and regeneration	Fear of injuries
	Avoiding unpleasant side effects
	General awareness of health risks
	Avoidance of pain
	Avoidance of toxins
	Observance of medical prescriptions
	Refusal of biomedical treatment
	Desire for wellness
Satisfaction of body protection and regeneration	Sense of physical safety
	Relief of symptoms/pain reduction
	Improved health in general
	No benefit from biomedical treatment
	Unpleasant sensations
	Injuries
Negligence towards health	Disregarding health protection to some extent
	Non-awareness of health risks
	Careless about prevention
	Neglecting treatment
	Resistance to commitments
	Accepting bad habits
Satisfaction of negligence towards health	Waste of energy and time
	Inconvenience
	Physical comfort

Table 4.3 (continued)

Food consumption	Improved appetite
	Preference of rich and tasty food
	Healthy diet
Satisfaction of food consumption	Enjoyment of meals
	Hungry in the evening after diet
Food abstinence	Diet to avoid health problems
	Diet to lose weight
	Diet without exaggeration
Satisfaction of food abstinence	Weight loss
	Failed attempts to lose weight
Influencing factors	
Physical conditions	Age-related diseases/chronic conditions
	Lack of energy
	Functional limitations
	Visual and hearing impairments
	Physical abilities
Psychological factors	Negative mood
	Knowledge deficit
	Language barriers
	Health literacy
External circumstances	Public information
	Access to facilities
	Financial issues
	Environmental features
Behavioural and attitudinal reactions	Domestic work
	Gardening
	Moving around
	Going for a walk
	Physical exercises
	Assistive devices
	Searching health-related information
	Massages
	Health resort/Spa
	Medical check-ups
	Medical treatment
	Therapeutic measures
	Complementary treatment
	Restricted consumption of alcohol
	Balanced diet
	Nutritional supplements
	Fasting
	Acceptance of limitations
	Resilience
	Denial

Janssen and Stube 2014), improved digestion (Belza et al. 2004), regular blood pressure (Belza et al. 2004; Graham and Connelly 2013), reduced cholesterol, improved blood glucose levels (Graham and Connelly 2013), relief of pain and other symptoms (Belza et al. 2004; Bethancourt et al. 2014), and as a consequence a reduced need for medicaments (Costello et al. 2011).

Given these benefits, many older persons expressed their *need for age appropriate exercises*. Physical activities should not be too strenuous as they could exceed physical capacities. They had to be adapted to functional limitations that older persons suffered from (Morris Docker 2006; Resnick et al. 2006; Mathews et al. 2010; Boggatz 2011; Price et al. 2011; Graham and Connelly 2013; Li et al. 2013; Janssen and Stube 2014; Nielsen et al. 2014; Patzelt et al. 2016; Barenfeld et al. 2017). Among the younger older persons, however, there was also a *desire to get rid of excess energy* through physical activities (Leavy and Aberg 2010; Mathews et al. 2010).

> Many old people in their fifties and sixties have a lot of energy, but they don't know where to go and have recreations…the government can organize classes to teach old people how to dance. Through dance classes, old people can be more physically active. (Mathews et al. 2010)

Some male older persons in this age group even saw physical exercises as a challenge and told about their tendency of *going to their limits* (Patzelt et al. 2016; Menichetti and Graffigna 2016; Boggatz and Meinhart 2017; Bredland et al. 2018).

> I say it just once, going to ones limits. For example, I do what I can … Yes, what can I do, and sometimes I experience while biking, for example, when I bike to Hildesheim or to Celle, which is 80 km, then think oh well, then (Patzelt et al. 2016)

The desire to perform a particular kind of physical activity made some of them even gradually consume their health;

> I don't have the illusion that mountaineering substitutes gymnastics. It's a one-sided activity; I feel it when I return from the mountains. My knees and my feet have become stiffer and I have to recover during the week. (Boggatz and Meinhart 2017)

4.2.1.2 Satisfaction of Physical Activity

Physical activities yielded an intrinsic satisfaction. Older persons described how they *enjoyed moving their body* while walking or performing exercises and such positive feelings even chased away negative moods (Berlin Hallrup et al. 2009; Hardy and Grogan 2009; Mathews et al. 2010; Miller 2010; Costello et al. 2011; Graham and Connelly 2013; Li et al. 2013; Söderhamn et al. 2013; Janssen and Stube 2014; Nielsen et al. 2014; Boggatz and Meinhart 2017).

> When I do Tai Chi sword, my body dances with the music, and the attractive physical posture provides me with a feeling of happiness and satisfaction. (Li et al. 2013)

> If I feel kind of depressed or something I go outside and do something and it always helps me. (Mathews et al. 2010)

Beside this immediate pleasure, older persons also reported about extrinsic effects they experienced after performing physical activities for a while. First of all they mentioned a *gain of energy* (Belza et al. 2004; Morris Docker 2006; Resnick et al. 2006; Hardy and Grogan 2009; Mathews et al. 2010; Dickinson et al. 2011; Nielsen et al. 2014; Komatsu et al. 2017). Efforts spent in exercising made them feel stronger:

> Exercising and walking gives you energy. That's how you strengthen your body. Your weakness disappears when you walk a lot. (Belza et al. 2004)

Such effects were sometimes felt immediately after finishing a structured group exercise:

> I always say I'm energized. I feel like a new woman, you do feel different. (Hardy and Grogan 2009)

This gain of strength could also have further positive consequences as in the case of Tai Chi exercises for fall prevention:

> I haven't had a fall and that's why I want to continue doing Tai Chi, because I think doing exercise like this helps me. I think it makes me stronger. My muscles, my leg muscles are stronger, I think. (Dickinson et al. 2011)

Gain of energy contributed to the second extrinsic effect experienced by older persons: *improved mobility*. Study participants reported reduced stiffness and decreased pain that had restricted their degree of mobility after joining an exercise group or using complementary treatments (Cartwright 2007; Resnick et al. 2006; Berlin Hallrup et al. 2009; Lorenc et al. 2012; Söderhamn et al. 2013; Simmonds et al. 2016; Boggatz and Meinhart 2017; Komatsu et al. 2017).

> My back is much better, I am more relaxed, to be able to lie there, and turn, was really nice. And then I had some trouble getting up… so, I needed some help with that in the beginning… but now, the last time I did it myself … and that's proof that it's good for me (Berlin Hallrup et al. 2009)

> I liked the exercise because I had a bad shoulder and when I started to exercise I could hang up the clothes a little bit. It did help me! (Resnick et al. 2006)

Others told about an improved balance after participation in fall prevention programs (Hutton et al. 2000; Morris Docker 2006). A final positive outcome of physical activities was that *getting tired after exercise improved sleep* (Hutton et al. 2000; Belza et al. 2004; Graham and Connelly 2013). In this way, physical activities triggered the need for rest and contributed to its satisfaction. If, however, older persons with a desire to get rid of energy could not satisfy this need, they complained about *restlessness due to excessive energy* (Berlin Hallrup et al. 2009; Leavy and Aberg 2010).

4.2.1.3 Physical Rest

To ensure physical well-being the need for physical activity had to be counterbalanced. Even fitness oriented older persons did not want to exaggerate physical exercise; they rather strove to *balance activity with rest* in order to recover (Frenn 1996; Boggatz and Meinhart 2017). Others were even less inclined to physical activities and had an explicit *desire for comfort and inertia* (Hutton et al. 2000; Lees et al. 2005; Resnick et al. 2006; Leavy and Aberg 2010; Mathews et al. 2010; Costello et al. 2011; Gilbert et al. 2012; Horne et al. 2013; Bethancourt et al. 2014; Menichetti and Graffigna 2016; Boggatz and Meinhart 2017) As they said, laziness and lack of discipline prevented them from exercising. For some of them this was a rather temporary mood. Others had gradually given up exercising and inertia became a habit so that they remained inactive despite better knowledge.

> I know that I should do sport, in the past I used to go to the gym but in the recent years, I finally chose the oratory and not the gym, whereas I know that this is not the better choice for me. (Menichetti and Graffigna 2016)

Some older persons, however, had never been used to exercises and preferred a sedentary lifestyle.

> I haven't got any will power. That's the biggest thing…. I would just rather sit and chat to my husband and watch television… I just can't be bothered. It just never enters my head. (Horne et al. 2013)

4.2.1.4 Satisfaction of Physical Rest

The need for physical rest was satisfied when older persons *recovered from efforts*. Those inclined to inactivity felt that due to their life-long work they had deserved such rest and they enjoyed to relax (Leavy and Aberg 2010). Older persons who suffered from functional limitations found some *physical relief with assistive devices*. Using a walker allowed them finding rest when needed (Brännström et al. 2013). If, however, older persons were not able to satisfy their need for rest they suffered from *overstrain*. This occurred mainly when they participated in activity groups with over demanding programs in relation to their abilities (Belza et al. 2004; Berlin Hallrup et al. 2009; Boggatz 2011; Costello et al. 2011; Horne et al. 2013; Bethancourt et al. 2014; Janssen and Stube 2014). But also those who went to their limits when doing physical exercises made sometimes similar experiences (Boggatz and Meinhart 2017; Bredland et al. 2018).

4.2.2 Body Protection and Regeneration Versus Negligence Towards Health

Physical activities were performed under the observance of the individual balance between body protection and regeneration on the one hand and negligence towards health on the other hand.

4.2.2.1 Body Protection and Regeneration

Older persons were aware that physical activities despite their apparent benefits for health could also result in physical harm. A major concern in this regard was *fear of* *injuries*, mainly falls that could occur while walking or exercising (Söderhamn 1998; Hutton et al. 2000; Belza et al. 2004; Lees et al. 2005; Berlin Hallrup et al. 2009; Hardy and Grogan 2009; Mathews et al. 2010; Miller 2010; Costello et al. 2011; Brännström et al. 2013; Horne et al. 2013; Bethancourt et al. 2014; Patzelt et al. 2016; Simmonds et al. 2016; Boggatz and Meinhart 2017; Bredland et al. 2018)

> Well I find that I am afraid of falling and being alone. I don't want to just lay there because I decided to do such and such as an exercise. (Mathews et al. 2010)

These fears were due to an awareness of either internal or external risk factors.

> When we get older, I know myself, you know, you don't have the balance. Many times you do something or walking and turn around and it feels like you almost could have landed on the floor. The balance isn't the same. (Miller 2010)

> I feel more alert if I go out for a while. I walk, I go up to the road crossing there … then, I turn and walk a couple of times. But, when it gets slippery I don't go there, then I only walk on this here little path to that little gate. (Berlin Hallrup et al. 2009)

Beside fear of injuries older persons were also concerned about *avoiding unpleasant side effects of exercise* (Hutton et al. 2000; Costello et al. 2011).

> I've heard that really after a certain age, probably running isn't particularly good for your joints…walking is probably better and will do less damage to your joints (Costello et al. 2011)

This concern for physical integrity was not restricted to situations when older persons performed physical activities. Rather, it was an expression of a *general awareness of health risks* that may come from factors other than stressful physical activity (Graham and Connelly 2013; Menichetti and Graffigna 2016; Simmonds et al. 2016).

> At a certain age, you have to start thinking about your health and yourself, sooner or later something happens … there is an exponential curve between age and health, and I'm at the point in which something will happen … so I'm aware that I want to live the last years fully and peacefully! (Menichetti and Graffigna 2016)

For some older persons this risk awareness was mainly aimed at the *avoidance of pain*, since pain was frightening and having no pain was equated to good health (Collins et al. 2004; Menichetti and Graffigna 2016). Others considered also potential threats to health that would show a negative impact on the long run. Caring about health and physical integrity meant for them the *avoidance of toxins* like alcohol or nicotine (Wang et al. 2001; Collins et al. 2004; Graham and Connelly 2013; Patzelt et al. 2016). *Observance of medical prescriptions* was a further way to care for physical integrity. These older persons regularly went to medical check-ups, took medications as prescribed, and followed advices for a healthy lifestyle (Collins et al. 2004; Horne et al. 2010; Gilbert et al. 2012; Graham and Connelly 2013; Söderhamn et al. 2013)

> Well, I suppose if the doctor said your health will deteriorate a lot if you don't start doing something, then I would have to seriously consider it (Horne et al. 2010)

By contrast, older persons who favoured complementary treatment believed that protecting their physical integrity required the refusal of biomedical treatment as this would harm their health (Belza et al. 2004; Cartwright 2007; Lorenc et al. 2012)

> The whole, holistic idea that your body is being treated, the whole body is being treated as well, and the mind […] you know, that is what I like about it and also not having chemicals I don’t really like chemical medicines, I know I have to take them but I would like to be totally un-chemical! (Cartwright 2007)

For some older persons, protecting and regenerating the body was not restricted to the prevention or treatment of diseases, they rather wanted to promote their health and had an explicit *desire for wellness* (Boggatz 2011). They took treatments at health resorts or spas to increase their vitality.

4.2.2.2 Satisfaction of Body Protection and Regeneration

The need for body protection and regeneration could be satisfied in a variety of ways. Older persons who were afraid of injuries could gain a *sense of physical safety*, for example, through exercises to improve their balance or when frailty prevented such improvements by using a walker (Morris Docker 2006; Brännström et al. 2013). Some of those who suffered from some kind of ailments reported about a *relief of symptoms* or *pain reduction* when they observed medical prescriptions, did exercises, or used a complementary treatment (Belza et al. 2004; Resnick et al. 2006; Cartwright 2007; Mathews et al. 2010; Lorenc et al. 2012; Boggatz and Meinhart 2017).

> Before I started this exercise program if I had pain I would just want to sit down. It has definitely changed my focus. Like in the morning now when I am stiff and sore I exercise! The instructor also taught us how to rub our sore joints (Resnick et al. 2006)

Others reported about an *improved health in general* as a consequence of exercises, lifestyle changes, or complementary treatments (Belza et al. 2004; Resnick et al. 2006; Cartwright 2007; Hardy and Grogan 2009; Leavy and Aberg 2010; Costello et al. 2011; Li et al. 2013; Nielsen et al. 2014). The need for physical integrity, however, was not always satisfied. There were also negative reports about the effects of treatments or preventive measures. Some older persons claimed that there was *no benefit from biomedical treatment* (Berlin Hallrup et al. 2009; van Leuven 2010; Lorenc et al. 2012).

> I do it just because I’ve been prescribed (take the medicine), I don’t believe in it, not much… it’s probably too late… I don’t think you can rebuild anything new on an old woman like me, I don’t … and I don’t notice any difference since I’ve taken these pills. (Berlin Hallrup et al. 2009)

The experience of ineffective treatments made some older persons more inclined to the use of complementary methods—at least for some kind of health problems:

> Doctors – I don’t think they offer much help for stress. (Lorenc et al. 2012)

Also exercises that were meant to promote physical health could result in *unpleasant sensations*.

> I felt afraid at first. I was afraid because I am a little bit heavy and I thought I would have a heart attack. I was afraid of shortness of breath. I got a little bit scared when she said drink a lot of water. I felt that something was going to happen to me and my heart beat faster. (Resnick et al. 2006)

In some cases older persons even suffered from *injuries* they wanted to avoid as a consequence of their health promoting activities (Horne et al. 2013).

4.2.2.3 Negligence Towards Health

The orientation to body protection and regeneration was counterbalanced in different degrees by negligence towards health. Some older persons admitted *disregarding health protection to some extent* (Price et al. 2011; Menichetti and Graffigna 2016; Boggatz and Meinhart 2017). They did not want to exaggerate health promoting activities, because they accepted age-related physical limitations. Hence, they allowed themselves some lack of discipline. Living a balanced and moderate lifestyle was their central concern.

> I say, you should live your life as you can. To worry about doing this or that, well… I eat healthy, I sometimes drink a glass of wine, I don't deny myself… but to worry about having this or that; I don't like it […] I let everything happen, it comes as it comes (Boggatz and Meinhart 2017)

Others showed a more or less conscious *non-awareness of health risks* (Berlin Hallrup et al. 2009; Miller 2010; Boggatz 2011; Menichetti and Graffigna 2016; Simmonds et al. 2016; Barenfeld et al. 2017). Some of them thought that they were not prone to particular risks and that recommendations to protect health pertained to other older persons. They simply believed that they did not belong to this age group or that potential risks did not apply to their own situation as it was described by an older woman who had received instruction for fall prevention.

> It's always about that woman going up the stairs and I don't go up the stairs anymore (Miller 2010)

Others simply disregarded advices despite better knowledge.

> I think that, I have to be careful so I don't fall … because my daughter says to me, 'Don't bother climbing your step ladder or this to take something down.' But, I do anyway when I can't reach. (Berlin Hallrup et al. 2009)

Taking care of their health became only relevant when they experienced noticeable symptoms. Otherwise they were *careless about disease prevention* (Menichetti and Graffigna 2016; Patzelt et al. 2016).

> I absolutely do not follow prevention, but if any serious illness came, I would be forced to change to regain my health. (Menichetti and Graffigna 2016)

Other older persons even neglected their treatment when they suffered from diseases (Boggatz 2011; Menichetti and Graffigna 2016). They were careless about symptoms and did not observe prescribed treatments because they did not understand its benefits as it was the case with a woman who suffered from a diabetic ulcer on her leg.

> Why should I keep a diet? I eat what I like… I don't need a diet… my weight is appropriate for my age and body size… otherwise my doctor would have told me… (Boggatz 2011)

This attitude was partly due to a lack of knowledge and partly due to the experience of physical displeasure resulting from restricted satisfaction of acquired habits and needs. Some older persons frankly admitted that they were comfortable with *accepting bad habits* like smoking or drinking alcohol even if these were detrimental to their health.

> I have some bad habits… that are by now in my routine and it is okay for me. (Menichetti and Graffigna 2016)

4.2.2.4 Satisfaction of Negligence Towards Health

The tendency to neglect one's health not met when older persons felt restricted by measures to protect their health. Some older persons believed that such efforts had no benefit and hence resulted in a *waste of energy and time* (Menichetti and Graffigna 2016; Lette et al. 2017).

> I think it's a waste to worry about things you won't be able to do […] not right now at least. […] Yeah, so I'm not really thinking about potential solutions I might someday need, because I would have to prepare for the entire repertoire and that would be a waste of energy. (Lette et al. 2017)

Others reported about *inconvenience* that made them give up measures to protect their health. Using walkers turned out to be complicated because one needed a larger space while walking and had to remember to bring the device and to lock the brakes (Brännström et al. 2013). In a similar way, wearing hip protectors made older persons feel clumsy or uncomfortable:

> I have hip protectors. They (the health service) want me to have that. But I don't want to. It feels very clumsy. (Berlin Hallrup et al. 2009)

> …and you see I always wear these sorts, this sort of a slipper but they hadn't got my size and she insisted that I have the little bootie one… I only took it to shut her up (laughs) and I gave it away to my friend. (Dickinson et al. 2011)

Although not mentioned explicitly it follows from what has been said above that negligence towards health conveyed a sense of *physical comfort*.

4.2.3 Food Consumption Versus Food Abstinence

Physical well-being depended also on a balance between food consumption and food abstinence which in turn was influenced by the individual balance between physical activity and rest.

4.2.3.1 Food Consumption

A consequence of physical activities was according to some older persons an *improved appetite* and hence a desire to eat (Belza et al. 2004; Komatsu et al. 2017). Exercise was, however, not a necessary prerequisite to trigger this desire. Some older persons had a *preference for rich and tasty food*. They used butter for frying and cream in gravy since these gave a better taste and they felt healthy, despite not eating according to present health recommendations (Gustafsson and Sidenvall 2002). Others, however, said that they were careful about their nutrition and paid attention to follow a *healthy diet* (Wang et al. 2001; Miller and Iris 2002; Belza et al. 2004; Collins et al. 2004; Söderhamn et al. 2011; Graham and Connelly 2013; Menichetti and Graffigna 2016; Boggatz and Meinhart 2017). The meaning of healthy diet, however, varied depending on individual and cultural habits. For some it was "not so much meat, also no sweets", but "preferably vegetables", for others it was rather "a lot of milk" (Boggatz and Meinhart 2017). A healthy diet could also include dietary supplements like Omega-3 or cod liver oil, calcium, and magnesium (Söderhamn et al. 2011).

4.2.3.2 Satisfaction of Food Consumption

The desire for food consumption was satisfied when older persons *enjoyed their meals* and this enjoyment was interpreted as a sign of health:

> I believe that how much you enjoy eating is an indicator of your well-being. Don't you think so? I really enjoy my meals (Komatsu et al. 2017)

If they, however, observed a diet, it could happen that they felt *hungry in the evening* and satisfied their need by eating (Gustafsson and Sidenvall 2002).

4.2.3.3 Food Abstinence

Despite their desire to eat, some older persons felt the necessity to observe a *diet to avoid health problems* (Gustafsson and Sidenvall 2002; Söderhamn et al. 2013; Patzelt et al. 2016)

> We like food. We really do. It should taste nice, of course. So I use butter and cream. I usually say to my husband, of course I can cook, but we have to cut down a bit. You can't go on like this all the time. (Gustafsson and Sidenvall 2002)

Diabetics hoped to maintain normal levels of blood glucose by observing a diet. Other older persons just had an interest in a temporary *diet to lose weight* (Boggatz 2011). But also here older persons just wanted a *diet without exaggeration*.

> I pay attention to my food. Some food is bad for me but I however eat it. (Menichetti and Graffigna 2016)

4.2.3.4 Satisfaction of Food Abstinence

If older succeeded in observing a diet they were happy about their *weight loss* which increased their physical and emotional well-being (Söderhamn 1998; Resnick et al. 2006).

> At midsummer I had lost 14 kg and felt satisfied in my body and soul […] I got better in my joints and the blood pressure was perfect. (Söderhamn 1998)

Those, however, who could not resist their desire to eat after being on diet all day complained about *failed attempts to lose weight*.

> And I tell you, I'm eating all this light stuff – I eat low-fat cheese, just 10% fat, and low-fat milk and everything, but I haven't lost a pound! (Gustafsson and Sidenvall 2002)

4.2.4 Influencing Factors

Health promotion and the satisfaction of body-related orientations of action depended on internal factors and external circumstances. Internal factors consisted of the older persons' physical condition and psychological factors like knowledge and mood. Among the external circumstances the availability of information, facilities, and finances were important.

4.2.4.1 Physical Condition

Not surprisingly, older persons' engagement in health promoting activities depended on their physical condition. *Age-related diseases* and *chronic conditions* were the most commonly reported barriers to physical activities (Hutton et al. 2000; Belza et al. 2004; Lees et al. 2005; Cartwright 2007; Leavy and Aberg 2010; Mathews et al. 2010: Boggatz 2011; Dickinson et al. 2011; Gilbert et al. 2012; Lorenc et al. 2012; Horne et al. 2013; Li et al. 2013; Lette et al. 2017). At the same time, however, they could trigger health awareness:

> I had a heart valve replacement and a stroke and while I got over it, I consequently had several bouts of congestive heart failure and dehydration put me in the hospital. I think that becoming very aware of how easy it is to get into trouble is probably one of the things that has made me able to live longer because I feel better than I had felt in a long time. I eat better; I watch my fluid because I have kidney failure… (Gilbert et al. 2012)

In some cases chronic conditions also made older persons use complementary treatments that were believed to be more effective than a biomedical approach (Cartwright 2007). Other older persons referred to a *lack of energy* (Belza et al. 2004; Leavy and Aberg 2010; Brännström et al. 2013; Barenfeld et al. 2017; Bredland et al. 2018) or *functional limitations* (Belza et al. 2004; Hardy and Grogan 2009; Leavy and Aberg 2010; Horne et al. 2013; Li et al. 2013; Bethancourt et al. 2014; Boggatz and Meinhart 2017) that resulted from age-related diseases when they were asked about factors influencing their physical activities. *Visual and hearing impairments* were a further physical condition that prevented older persons from exercising (Belza et al. 2004; Lees et al. 2005). It goes without saying that physical abilities were a resource and supported participation in physical activities (Barenfeld et al. 2017).

4.2.4.2 Psychological Factors

Beside physical conditions there were also psychological factors that influenced the level of physical activities. Some older persons told how *negative moods* caused them to become inactive (Barenfeld et al. 2017). *Knowledge deficits* about health issues supported inattentiveness to health problems and their prevention (Horne et al. 2010: Miller 2010; Boggatz 2011; Price et al. 2011; Patzelt et al. 2016; Barenfeld et al. 2017). Such knowledge deficits were intensified by *language barriers* among migrants who had grown old in a foreign country (Dickinson et al. 2011). *Knowledge about health*, on the other hand, was a promoting factor for physical activities (Maddox 1999; Price et al. 2011; Bethancourt et al. 2014).

4.2.4.3 External Circumstances

A variety of external circumstances influenced older persons' body-related orientations of action. Access to *public information* could support an engagement in health promoting activities. The required information concerned both methods to stay healthy in general, and local programs that supported older persons in doing so. Older persons obtained such information from newspapers, health-related books, brochures, and sometimes also from the internet (Frenn 1996; Wang et al. 2001; Leavy and Aberg 2010; Lette et al. 2017). Others complained about difficulties to obtain required information, especially when information was mainly available from the internet.

> You have to seek it [i.e. information] yourself, and a lot of people in my generation don't buy the newspaper […] they don't have computers either and can't afford to buy them. So we can't keep up, we get left behind, we who were born in the 20s or 30s. (Leavy and Aberg 2010)

> Everybody expects that we all have computers and we are all on the internet. And we're not. Especially in the rural areas, because you don't get high-speed internet (Berry et al. 2009)

Participation in health promotion programs could be facilitated or impeded by the *access to facilities*. Physical effort required to reach a particular program was an issue. Hence, programs offered in the vicinities were perceived as inviting (Hutton et al. 2000; Mathews et al. 2010; Costello et al. 2011; Dickinson et al. 2011; Li et al. 2013; Bethancourt et al. 2014; Patzelt et al. 2016; Barenfeld et al. 2017; Boggatz and Meinhart 2017).

> I think the exercise classes need to be community based. Age Concern had the idea of getting little groups going here and there in church halls and community halls and so forth, that's grass roots stuff, that's where the classes need to be. They need to be small they need to be local. (Hutton et al. 2000)

If health promotion programs were rather far away from the place of living lack of convenient public transportation could prevent older persons from participation (Hutton et al. 2000; Mathews et al. 2010; Horne et al. 2013; Janssen and Stube 2014).

Financial issues also influenced participation in such programs (Hutton et al. 2000; Söderhamn et al. 2011; Barenfeld et al. 2017; Lette et al. 2017). They were attractive if they were free of cost or available at reasonable prices (Horne et al. 2010; Mathews et al. 2010; Boggatz 2011; Costello et al. 2011; Dickinson et al. 2011). Quite often, however, older persons perceived them to be too expensive and they could not to afford them (Frenn 1996; Belza et al. 2004; Cartwright 2007; Hardy and Grogan 2009; Mathews et al. 2010: Boggatz 2011; Li et al. 2013; Bethancourt et al. 2014; Janssen and Stube 2014; Patzelt et al. 2016; Boggatz and Meinhart 2017).

> I would like to see a, a gym that I can afford. They have gyms, but I can't afford to join one. (Mathews et al. 2010)

The performance of individual physical activities depended on *environmental features*. Access to aesthetically pleasing places with flat, even surfaces and available resting spots encouraged older persons to remain physically active (Mathews et al. 2010; Costello et al. 2011; Gilbert et al. 2012; Graham and Connelly 2013; Bethancourt et al. 2014).

> I am blessed to be living in this environment. Everything is so close, food is next door and there are no stairs. (Gilbert et al. 2012)

Other older persons perceived their environment as hazardous to health. They complained about obstacles like uneven surfaces on the sidewalks that caused fear of falling. (Gilbert et al. 2012; Brännström et al. 2013; Bethancourt et al. 2014; Janssen and Stube 2014). No available space, air pollution, and too much traffic were described as hindrances for outdoor activities in bigger cities (Leavy and Aberg 2010; Mathews et al. 2010; Li et al. 2013; Bredland et al. 2018). Bad weather, gravel, ice, and snow were impeding factors regardless of the place of living (Belza et al. 2004; Brännström et al. 2013; Bredland et al. 2018).

4.2.5 Behavioural and Attitudinal Reactions

If older persons could not satisfy their body-related needs or perceived them to be under threat they showed a variety of behavioural and attitudinal responses. When asked how they met their need for physical activity, many of them said that they performed everyday activities like *domestic work* (Frenn 1996; Grasser and Craft 2000; Wang et al. 2001; Miller and Iris 2002; Leavy and Aberg 2010; van Leuven 2010: Boggatz 2011; Söderhamn et al. 2011; Li et al. 2013; Patzelt et al. 2016; Boggatz and Meinhart 2017), *gardening* (Maddox 1999; Söderhamn et al. 2011; Patzelt et al. 2016), and *moving around* to accomplish affairs (Belza et al. 2004; Boggatz 2011; Li et al. 2013). Some believed that these daily routines were sufficient to stay healthy, others, however, performed additional activities to maintain their fitness. *Going for a walk* was common (Frenn 1996; Grasser and Craft 2000; Costello et al. 2011; Price et al. 2011; Söderhamn et al. 2011; Gilbert et al. 2012; Graham and Connelly 2013; Barenfeld et al. 2017; Boggatz and Meinhart 2017).

Physical exercises were also mentioned quite often. According to the abilities of the older persons they consisted of biking, swimming, jogging, Nordic walking, training in a fitness studio, dancing, aerobic, gymnastics, Tai Chi, Yoga, or chair-based exercises (Frenn 1996; Grasser and Craft 2000; Wang et al. 2001; Miller and Iris 2002; Belza et al. 2004; Collins et al. 2004; Leavy and Aberg 2010; van Leuven 2010; Boggatz 2011; Costello et al. 2011; Price et al. 2011; Söderhamn et al. 2011; Gilbert et al. 2012; Li et al. 2013; Nielsen et al. 2014; Janssen and Stube 2014; Patzelt et al. 2016; Boggatz and Meinhart 2017). In case of functional limitations older persons used *assistive devices* like canes or walkers to reduce efforts when moving around and to protect the body against falls (Berlin Hallrup et al. 2009; Miller 2010; Söderhamn et al. 2011; Graham and Connelly 2013; Boggatz and Meinhart 2017). In some cases, older persons who were concerned about protecting their physical integrity actively *searched health-related information* by reading brochures or visiting lectures or courses about health (Grasser and Craft 2000; Wang et al. 2001; Patzelt et al. 2016). If older persons had a desire for wellness they wanted to have *massages* (Resnick et al. 2006) or went to a *health resort or spa* (Boggatz 2011). *Medical check-ups* were used for the early detection and prevention of diseases (Wang et al. 2001; Collins et al. 2004; van Leuven 2010; Boggatz 2011; Söderhamn et al. 2011; Gilbert et al. 2012) and in case of sickness they searched for *medical treatment*, went to their physician, and took medication as prescribed (Frenn 1996; Wang et al. 2001; Boggatz 2011; Söderhamn et al. 2011; Gilbert et al. 2012; Patzelt et al. 2016). If necessary, they also followed other therapeutic measures like physiotherapy (Boggatz 2011; Gilbert et al. 2012). *Complementary treatment* was used when biomedical approaches had failed to succeed or when they were perceived as not compatible with a holistic idea about health (Cartwright 2007; Lorenc et al. 2012; Patzelt et al. 2016; Boggatz and Meinhart 2017). Further measures to protect physical integrity were *to stop smoking* and a *reduced consumption of alcohol* (Wang et al. 2001; Patzelt et al. 2016). Regarding the consumption of and abstinence from food older persons claimed to observe a *balanced diet* (Grasser and Craft 2000; Miller and Iris 2002; van Leuven 2010; Boggatz 2011; Söderhamn et al. 2011; Gilbert et al. 2012; Patzelt et al. 2016). Some of them took also *nutritional supplements* like vitamins or glucosamine (Wang et al. 2001; Lorenc et al. 2012; Simmonds et al. 2016), whereas others made efforts of *fasting* in order to lose weight (Söderhamn 1998; Boggatz 2011).

These health-related activities, however, were not always successful. If older persons could not satisfy their desire to maintain physical activities they began to *accept their physical limitations* (Söderhamn 1998; Wang et al. 2001; Söderhamn et al. 2011; Boggatz and Meinhart 2017; Menichetti and Graffigna 2016). This attitudinal reaction corresponded to a tendency to critical self-perception which is an identity-related orientation of action, as we will see below. On the other hand, there were also older persons who were less inclined to give up. They wanted to maintain their physical activities despite limitations and hence resorted to *resilience* (Collins et al. 2004; Cartwright 2007; Leavy and Aberg 2010; Gilbert et al. 2012; Söderhamn et al. 2013). Although they had to slow down, they were not ready to give up and struggled to remain active as much as possible.

> My body betrays me sometimes, I guess by 81, you kind of slow down. You do just have to stay with it. If you don't stay with it, boy you are lost.
>
> I've got a bad leg, and it doesn't keep me from walking but it keeps me from walking far. (Gilbert et al. 2012)

Others, however, were not willing to face their health problems and tried to deal with them by *denial* which resulted in delayed help seeking:

> When I'm sick, I avoid thinking about this and do nothing (Menichetti and Graffigna 2016)

> We have been taught that we men should put up with things more than women and accept our situation, even though we have heard it is important to get early help, like seeing a doctor or a physiotherapist. (Bredland et al. 2018)

This attitude was not restricted to men as the quotation above suggests. To some extent, also women were reported to ignore health risks despite better knowledge, for example, when they became aware of their risk of falling.

> … it's nothing I think about every day, that I'm very fragile … It's just to think I'm going to try to manage on my own and not fall … I soon will have to give up, that's nothing I go around thinking about … no, I really don't. (Berlin Hallrup et al. 2009)

4.3 Health Promotion and Social Orientations of Action

Although health promotion programs as described above focused on the physical aspect of health, older persons did not only regard their body-related orientations of action when they considered participation. Health promotion was a social activity and therefore it also concerned older persons' social orientations of action. The satisfaction of social orientations of action was not only perceived as a precondition for health promotion, for many older persons it rather contributed directly to their health. Health promotion meant for them to enjoy social contacts and to have privacy, to be self-reliant and to receive care when necessary, to be in control of their health promoting activities without becoming a burden for others, and to adjust to social norms while at the same time enjoying some unconventionality. For this reason, it was not possible to promote physical fitness without paying attention to the satisfaction of social needs. As above, Table 4.4 provides an overview over the aspects of each orientation of action, their influencing factors, and the behavioural and attitudinal responses of the older persons.

4.3.1 Self-Reliance Versus Being Cared for

4.3.1.1 Self-Reliance

As we saw in the previous chapter, the *desire to remain self-reliant* was of central concern for older persons. It also came to the fore in the context of health promotion (Maddox 1999; Wang et al. 2001; Collins et al. 2004; Cartwright 2007; Price et al.

Table 4.4 Social orientations of action, influencing factors, behavioural and attitudinal reactions

Orientations of action and their satisfaction	
Self-reliance	Desire to remain self-reliant
	Taking responsibility for their health
	Proactive search for health-related information
	Remaining passive
Satisfaction of self-reliance	Remaining independent
	Sense of self-efficacy
	Disabled by an overprotective environment
	Losing the sense of self-efficacy
Being cared for	Desire for being cared for
	Desire for guidance and encouragement
	Desire for credible sources
	Rejection of unsettling messages
	Desire for a safe environment
Satisfaction of being cared for	Feeling safe during treatment
	Feeling safe through careful coaching
	Being encouraged by family members
	Encouragement from peers
	Lack of guidance and encouragement
	Uncertainty caused by public information
	Security provided by social network
	Fear to be abandoned
	Fear of crime
Exerting influence on others	Remaining in control over prevention and treatment
	Rejection of advice
	Having choices
	Imposing group norms on others
Satisfaction of exerting influence on others	Being empowered to make own decision
	Being encouraged to express one's opinion
	Informed performance
	Feeling exposed to a pressure to comply
	Exposed to pressure from overprotective environment
Attention to the needs of others	Fear to become a burden
	Getting health-related information without bothering others
Satisfaction of attention to the needs of others	Feeling indebted
Social adjustment	Adherence to social norms
	Adaptation to expectations of significant others
	Sense of obligation towards a group
	Need to be accountable
	Observing own cultural norms when participating
Satisfaction of social adjustment	Gaining an inner structure
	Loss of discipline
	Feeling guilty due to non-observance
	Conflict with own cultural norms

(continued)

Table 4.4 (continued)

Unconventionality	Some neglect of rules and regulations
	Unconventional way of ageing
	Disregarding advices
Satisfaction of unconventionality	Own way of life
	Feeling constrained by schedules and regulations
Closeness	Desire to socialize
	To become an integrated group member
	Desire for contact with younger persons
	Maintaining relationships with unsportsmanlike friends
Satisfaction of closeness	Gaining contacts
	Social bonds
	Positive relationship with instructor
	Lack of social contacts
	No partner
	No sense of belonging
Distance	Preferring social distance
	Desire for private exercise
	Deterred by overcrowded events
	Separating the desire for exercise from the desire for social contact
Satisfaction of distance	Being able to maintain privacy
Influencing factors	
Physical and psychological factors	*Same as in Table 4.3 under physical condition and psychological factors*
External circumstances	Social network
	Organizational matters
	Quality of care
	Features of the social environment
Behavioural and attitudinal reactions	Participation in group activities
	Home based exercises
	Fitness studio
	Accepting limitations
	Resilience

2011; Graham and Connelly 2013; Patzelt et al. 2016; Boggatz and Meinhart 2017; Lette et al. 2017). Older persons even equated independence and health.

> A person is healthy if they are able to take care of themselves
>
> Health is being independent and being myself; not what someone else wants me to be or do (Collins et al. 2004)

In other words, physical fitness was not an end in itself. It allowed remaining mobile and doing what was desired. Remaining independent was the deeper meaning of all efforts to promote physical activity. It was, however, not only the aim of health promotion, it also shaped the way how older persons approached this issue. Those with a strong desire for independence motivated themselves to exercise and were ready to *take responsibility for their health* (van Leuven 2010; Gilbert et al. 2012; Simmonds et al. 2016; Patzelt et al. 2016; Lette et al. 2017)

> I don't have anybody saying you can't do this or you can't do that, so that's me. (Gilbert et al. 2012)

> No, that's your own responsibility. You'd need to pull yourself up by the bootstraps. (Lette et al. 2017)

Sometimes, the awareness of their own responsibility was triggered by a critical incident that made older persons rethink their way of life—as in the case of an older man who stopped drinking:

> I began to get periods of black-outs and I did not know where I was. I then understood that if I did not do something drastic, it was all finished … (Söderhamn et al. 2013)

Some of these older persons also told about their *proactive search for health-related information*, which was another way of assuming responsibility (Miller 2010; McGrath et al. 2016; Menichetti and Graffigna 2016; Patzelt et al. 2016; Lette et al. 2017). Some went to the health insurance office to request information and take home brochures. Others searched the internet or they learned about services either through talking to other people or by observing developments in their local community. On the other hand, there were also older persons who were less inclined to become active regarding their health. Although they would not deny their desire for independence, they *remained passive* and did not take the initiative, because they attributed their complaints to their age and believed that they could not influence their health through their own activities (Boggatz 2011; Menichetti and Graffigna 2016).

> It is useless to worry about what may happen and what can be done to prevent mishaps… cancer or other diseases can occur also if you have an optimal lifestyle… (Menichetti and Graffigna 2016)

If they relied on anything at all, it was on taking medication to improve their condition.

> Well, what shall you do when you're growing old… There is not so much that can be done… you may take some pills, and go from one doctor to another… that's all. (Boggatz 2011)

4.3.1.2 Satisfaction of Self-Reliance

The desire for independence was satisfied when older person succeeded in *remaining independent* and when they attributed this success to their health promotion efforts (Graham and Connelly 2013). Furthermore they could also achieve a *sense of self-efficacy* regarding the performance of health promoting activities (Belza et al. 2004; Resnick et al. 2006; Menichetti and Graffigna 2016; Barenfeld et al. 2017) They gained self-confidence and inner strength by practicing.

> By doing the exercise it gave me my confidence back in my ability to exercise. (Resnick et al. 2006)

On the other hand, there were older persons who could not satisfy their desire for independence despite their attempt to do so. They felt *disabled by an overprotective environment* that tried to relieve them of all efforts and duties considered to be too difficult. (Bredland et al. 2018). Some older persons, for example, told how their neighbours shovelled away snow in the wintertime in front of their house or how they came up the stairs every morning with the newspaper—and how such well-meant help restricted at the same time their self-reliance.

> She is so helpful, however, I needed and would have enjoyed that activity. Now I have no reason to walk down the stairs every morning. (Bredland et al. 2018)

On the long run, overprotective environments could undermine older persons trust in their self-reliance and ability to decide for themselves.

> When we are seniors we seem to be more sensitive to how our family and friends think we should behave, I am trusting my own judgement less and less (Bredland et al. 2018)

There were also those who had *lost their sense of self-efficacy* and did not believe that they were still able to exercise (Mathews et al. 2010; Horne et al. 2013). In some cases, this attitude became a habit and as a consequence these older persons developed an external locus of control that made them remain passive. Unable to satisfy their desire for independence, they resigned and gave up.

4.3.1.3 Being Cared for

The desire for independence was counterbalanced by a *desire for being cared for* that influenced the health behaviour. Older persons wanted to have access to their family doctor, to hospitals, and to care homes in the neighbourhood in order to be treated by skilled health care professionals in a way that was adapted to their individual needs (Söderhamn et al. 2011). To be called to the physician for check-ups and continuous visits provided a feeling of security (ibid). In short, they felt relieved if others took some part of the responsibility for their health. The same need was apparent regarding their participation in health promotion programs. Here, they expressed a *desire for guidance and encouragement* (Hutton et al. 2000; Horne et al. 2010; Mathews et al. 2010; Dickinson et al. 2011; Söderhamn et al. 2013; Patzelt et al. 2016; Simmonds et al. 2016; Bredland et al. 2018) According to these older persons, guidance was necessary to make them join such programs and to get them to perform exercises correctly. In the first case, physicians were of central importance as advisors, in the second case instructors and trainers.

> I would do it if it was on the doctor's recommendation, yes. If he thought I was capable of doing it… I wouldn't undertake it unless I was advised. Or unless I confirmed it was safe to do it. (Simmonds et al. 2016)

> I would go to the gym if I had one-to-one…a personal trainer. If I'm doing all these things I'm thinking have I done enough or have I not done enough… I need someone to tell me, 'right now, you do six weeks of these and you will be really good and toned up. (Horne et al. 2010)

Such guidance, however, was not perceived to be an external control that restricted the older persons' self-determination. It was rather an emotional support and encouragement that helped them to overcome their inertia and gave them a sense of self-efficacy.

> Not necessarily an instructor but somebody there, you know, to say do this and that and that. You know, like you're a five year old child. Saying "come on, come on"… I need a bit of encouragement, because I put myself back [doesn't push himself]. (Horne et al. 2010)

The desire to be cared for was often related to a need for security that should be provided by others. This was apparent when older persons talked about health-related information that was available in the media. They expressed a *desire for credible sources* such as associations of retired persons, the medical association, universities, or clinics that had a reputation of trustworthiness (Berry et al. 2009; Price et al. 2011). The same desire for security was apparent in their *rejection of unsettling messages*, that created rather fear of diseases than trust in possibilities to prevent them (Berry et al. 2009; Price et al. 2011). Security was also of importance if older persons wanted to perform outdoor activities. Some were afraid of social threats like rape or robbery and expressed in this way their *desire for a safe environment* (Belza et al. 2004; Hardy and Grogan 2009).

4.3.1.4 Satisfaction of Being Cared for

The desire for being cared for and for security was satisfied in a variety of ways. Regarding medical care some older persons reported how they *felt safe during treatment* if they had a stable relationship to their family doctor (Frenn 1996; Cartwright 2007; Berlin Hallrup et al. 2009; Horne et al. 2010; Lorenc et al. 2012).

> When you have a doctor, it's nice to see the same one .... It feels safe, yes it does, because he knows exactly what my life is like. (Berlin Hallrup et al. 2009)

The same feeling of security was reported by some of those who preferred alternative treatments.

> I think it's somewhere to go where I get treatment that I find valuable, and people who listen and time spent, and the confidence I feel in it, I feel safe here, comfortable. (Cartwright 2007)

If older persons participated in health promoting exercise programs they *felt safe through careful coaching* (Resnick et al. 2006; Dickinson et al. 2011).

> Having the instructor made me feel safer. She would tell you how much you could take, how much time. I felt that she knew what she was doing. Some people just let you exercise to take your money. She would not push you. She would help you. (Resnick et al. 2006)

Most of all, however, the need for support was satisfied by the encouragement of significant others. Many older persons told how they were *encouraged by family members* to exercise and join activity groups (Miller and Iris 2002; Belza et al. 2004; Shearer and Fleury 2006; Miller 2010; Price et al. 2011; Li et al. 2013;

Söderhamn et al. 2013; Bethancourt et al. 2014). Even more important was the *encouragement from peers* who participated in the same program (Hutton et al. 2000; Miller and Iris 2002; Belza et al. 2004; Resnick et al. 2006; Hardy and Grogan 2009;; Shearer and Fleury 2006; Mathews et al. 2010; Costello et al. 2011; Price et al. 2011; Söderhamn et al. 2011; Horne et al. 2013; Li et al. 2013; Bethancourt et al. 2014; Patzelt et al. 2016; Komatsu et al. 2017).

> The motivation from one person to the next is important. When you come to the class and you see others doing the exercise it helps. We lift each other up and push each other along. (Resnick et al. 2006)

On the other hand, there was also *lack of guidance and encouragement* (Horne et al. 2010, 2013; Leavy and Aberg 2010; Lorenc et al. 2012; Bethancourt et al. 2014). Older persons complained about physicians who gave only insufficient advice about the appropriate level of exercise and about training facilities where participants did not get their due attention.

> The nurse gave me a prescription for exercise. I took it down to X Street but there is no supervisor for the gym and there are only two machines. So I stopped going. (Horne et al. 2010)

Superficial diagnoses and advices that simply attributed problems to old age could have a discouraging effect, because older persons did not feel to be taken seriously and to be cared for.

> I think sometimes the medical profession are too quick to look at your age and say 'you've got to this age', […] I think sometimes they are too quick to jump in and say, 'oh well it's deterioration' and that de-motivates people [to exercise] and I was de-motivated then. (Horne et al. 2010)

In a similar way, some older persons complained about *uncertainty caused by public information* spread in the media (Gustafsson and Sidenvall 2002; Berry et al. 2009; Price et al. 2011). Advices were perceived as inconsistent or even scaring. Regarding recommendations for healthy nutrition one older woman observed:

> I suppose some of it is good, but it is almost too much. They frighten you so you get scared of everything. (Gustafsson and Sidenvall 2002)

A final aspect concerned the *security provided by the social network*. Staying in a familiar neighbourhood gave older persons a feeling of being protected:

> Well see, the comfort of having lived somewhere for a long time, such as I have now, is knowing people very well. Thus [I am aware that] they know that when I need help with something, it's okay for me to come to their door and ask: Would you mind helping me for a minute or would you mind doing this for me? (Lette et al. 2017)

Less familiar environments, however, caused a *fear of being abandoned* in case of health hazards.

> What would I do if I fell? I am not sure that I can call them (the children), or them over there (the neighbours) … but it's not for certain that they'll ring and care about me. I might end up lying there. (Berlin Hallrup et al. 2009)

Some older persons even perceived their environment as a threat to social security and had a *fear of crime* that prevented them from outdoor activities (Belza et al. 2004; Hardy and Grogan 2009). All these cases show that older persons felt enabled to promote their health if their desire for being cared for and for security was met. In other words, a reasonable degree of care was necessary to promote their self-reliance.

4.3.2 Exerting Influence on Others Versus Attention to the Needs of Others

4.3.2.1 Exerting Influence on Others

When older persons participated in health promotion programs their need for staying in control of the situaton and exerting influence on those who were responsible for these programs become important. This was apparent in their reaction to medical check-ups and treatment. They disliked having help and support imposed upon them and preferred to *remain in control over preventive measures and treatment*.

> So she'd make a plan based on what she thinks is necessary, but she won't overrule me, she always tells me what she's going to do and why, and I like that. That way, you're respected as a person and that's very important to me. (Lette et al. 2017)

In some cases the desire for self-assertion and control resulted in a complete *rejection of advices* (Boggatz 2011; Menichetti and Graffigna 2016).

> No matter who would tell me, you have to eat fruits, you have to do this and I do not know … drink juice … but I don't, no … because I don't want … I've got my own head (Boggatz 2011)

Other older persons were less dismissive, but in order to remain in control they wanted to *have choices* regarding both the person who gave advices and the kind and extent of recommended activities (Cartwright 2007; Miller 2010; Price et al. 2011; Patzelt et al. 2016; Lette et al. 2017).

> I choose where I get my advice and I choose the workshops I attend. (Miller 2010)

Having choices also meant having enough time to think about participation and to consider pros and cons when being invited to join a health promotion program.

> So I would prefer to be informed specifically by written notice. … I ended up lying there. I can read, I've got all day. Then they can leave me two days' time to answer. (Patzelt et al. 2016)

A desire to exert influence was also apparent when older persons were members in an activity group, identified with the group's unwritten rules, and *imposed group norms on others* (Nielsen et al. 2014). Newcomers were expected to comply or they demanded their exclusion.

> It (our football team) is very closed and the environments (in sports associations) are very closed. They are closed for various reasons, exactly like we are. You know what you have, when you meet; it works. You're dependent on a certain number of people. If you get some people who come and go and such, it will ruin everything. So, one is very careful to get something that works. That's also what we did here. (Nielsen et al. 2014)

4.3.2.2 Satisfaction of Exerting Influence on Others

The desire to exert influence on others and to stay in control was satisfied, when older persons felt *empowered to make their own decision*. This was the case when they found persons who did not command them but listened instead and gave them a chance to express thoughts and feelings.

> Family likes to boss me around. Friends pat you on the back, we listen to each other, and we don't laugh without each other. (Shearer and Fleury 2006)

Such non-directive relationships provided an open space where older persons could reflect upon their needs in order to come to a decision. They made this experience in informal relationships but also in health promotion programs when they *were encouraged to express their opinion* by trainers or instructors (Barenfeld et al. 2015). Expressing their needs and getting explanations about the reasons why something should be done in a particular way resulted in an *informed performance* of activities, that gave them a feeling of being in control despite receiving instructions (Resnick et al. 2006; Söderhamn et al. 2013).

> It was also helpful that she told us what to do and why we were doing it. She told us this exercise is for the heart and this is for the legs and she told us to drink a lot of water. When she noticed we were not doing it right she would tell us that. (Resnick et al. 2006)

In this case, the care of the instructor did not result in a feeling of being controlled because she strengthened the sense of self-efficacy and independence of the older person. In other cases, however, older persons *felt exposed to a pressure to comply* with health-related norms and advices. This occurred when a trainer or therapist was too demanding (Miller 2010; Horne et al. 2013) or when the performance level of an activity group was above the capabilities of the older person and a competitive atmosphere created a pressure to perform although they felt unable to keep pace (Hutton et al. 2000).

> I don't like therapists. They're pushy. I don't like pushy (Miller 2010)

> Some people try to push you into it without going into why you don't want to do it. (Horne et al. 2013)

External pressure could also prevent older people from engaging in physical activity. Those who told how they had a feeling of being disabled by the well-meant help of families or friends, sometimes also felt *exposed to pressure from these overprotective environments* (Grasser and Craft 2000; Bredland et al. 2018). Family members sometimes stopped their physical activities out of fear that an accident might happen. In some cases a previous accident was the cause of worry, in other cases simply excessive anxiety.

> After that, I was never permitted to take a shower without Amy (a niece who shared her home) being around. It was terrible…terrible…very frustrating because I have always been a very independent person…but I thought this was just the most horrifying experience and since then I am deathly afraid… I just hope I never fall again…because I do not ever want to be incapacitated again… (Grasser and Craft 2000)

> My children won't let me walk in the woods alone, as I have always loved to do. (Bredland et al. 2018)

> When I want to do a little work outside the house, she's always watching and telling me to be careful. (ibid.)

A permanent supervision not only restricted the self-determination of older persons, it could also result in a loss of their self-reliance.

4.3.2.3 Attention to the Need of Others

Despite their desire to exert influence on others older persons were generally not inclined to exert pressure on them. Being aware of their needs they disliked to be too demanding in case they should need help and *feared to become a burden* (Söderhamn 1998; Grasser and Craft 2000; Berlin Hallrup et al. 2009; Price et al. 2011; Lette et al. 2017). As a consequence they refrained from asking for help:

> I don't drive so I have to ask others for a ride… oh, I haven't asked anyone because I'm just one block from the bus line and I just take the bus… If the weather is real nasty, I would just have to call and cancel it… I'm not going to ask anyone to help me, not yet. (Grasser and Craft 2000)

Some of them attributed this attitude to the climate of individualism and social distance in Western societies.

> I think the problem is, at least here in the Netherlands, I barely ever see my neighbours. Do you think I would ask them if I ever needed something? No, I wouldn't do that. (Lette et al. 2017)

This attitude came also to the fore when older persons tried to *get health-related information without bothering others* who could provide such information since they were knowledgeable insiders at official places.

> …and very often if you have a very keen interest, the receptionist or somebody like that would be happy to give advice. Then again, you'd have to use a bit of common sense and don't be bothering them when they're busy and maybe wait until the mad rush is over and then go over and have a chat with them. (McGrath et al. 2016)

4.3.2.4 Satisfaction of Attention to the Needs of Others

In some cases older persons were not able to satisfy their desire to pay attention to the need of others. When they received their help they *felt indebted* because they saw it as their duty to reciprocate and were at the same time afraid that they could not (Grasser and Craft 2000).

4.3.3 Social Adjustment Versus Unconventionality

4.3.3.1 Social Adjustment

When older persons made efforts to promote their health it was often an attempt to adjust their behaviour to social norms and expectations. *Adherence to social norms* could induce them to engage in activities in which they took less pleasure. If they kept a diet, for example, they were partly motivated by adapting to a beauty ideal that prevailed in Western societies (Patzelt et al. 2016). In a similar way, some older persons perceived physical activity to be a duty they had to observe regardless of whether they liked it or not. For them, it was an unwritten rule that one had to stay active in order to lead a socially acceptable life (Menichetti and Graffigna 2016; Bredland et al. 2018). Social norms are often conveyed via the social network. Hence, adjustment to social norms often occurred as an *adaptation to the expectation of significant others* like family members or friends. Some older persons told that they would listen to the advices of their children regarding the protection of their health (Miller 2010). Others performed alternative practices like kinesiology half-heartedly because they had been influenced by a friend who was convinced of this method (Boggatz and Meinhart 2017). Adjustment to social norms also occurred when older persons became a member of an activity group. Being a group member sometimes meant to have a common goal that created a *sense of obligation towards the group* and forced its members to "pull together" (Resnick et al. 2006; Shearer and Fleury 2006; Nielsen et al. 2014).

Feeling obliged to meet social expectations was perceived as helpful for maintaining discipline by some older persons. For this reason they expressed their *need to be accountable* to someone—preferably the instructor of an activity group who had sufficient authority to convey rules of the group.

> We need supervision! We need the instructor to help us keep it up or else we do not do it. At least once a week we need that external boost. It is not easy to do the exercise on your own! (Resnick et al. 2006)

A similar motive came to the fore when older persons told about their *obedience to medical experts*. They felt obliged to comply with their physicians prescriptions because he or she had more knowledge and authority to convey rules for a healthy lifestyle.

Adjustment to social norms was, however, not always supportive for health promotion. Social norms could also restrict or prevent participation in such programs. Older immigrants who were not familiar with cultural habits in Western countries wanted to *observe their own cultural norms when participating* in health promotion programs. Muslim Asian women, for example, were concerned about gender segregation and expected that no men were in the group (Dickinson et al. 2011).

4.3.3.2 Satisfaction of Social Adjustment

The desire for social adjustment was satisfied when older persons *gained an inner structure* that shaped their behaviour and kept them on track. Their initial observance of health-related activities was not due to an increased sense of self-efficacy but due to a sense of being controlled by some kind of authority that deserved respect. After some time as a member of an activity group, however, they internalized a required discipline that made them comply with rules rather automatically and without efforts to overcome an inner resistance. Health promoting activities thus became a habit.

> It is just something you do without reflecting, negotiating and making the choice every time. (Nielsen et al. 2014)

Maintaining such habits depended, however, on an external source of control. If an activity group interrupted its activity or terminated its existence the older persons felt that they were *losing their discipline* and gave up exercising (Nielsen et al. 2014). In a similar way, lack of permanent control by a physician could result in abandoning a prescribed treatment.

> But the doctor that did these investigations on osteoporosis wasn't here for very long. Then he wasn't here anymore, they (the carers) thought that we'd care about the medication. But, anyway … I stopped taking it. Because I didn't hear from him (the doctor) again… (Berlin Hallrup et al. 2009)

In some cases older persons *felt guilty for a non-observance* of health-related recommendations. They wanted to adapt to social norms of healthy behaviour but failed to do so due to lack of discipline (Menichetti and Graffigna 2016). Older women, for example, who tried to keep a diet during the day felt hungry in the evening, gave in to their desire and later accused themselves for their failure (Gustafsson and Sidenvall 2002).

For older immigrants, participation in health promotion programs did not always meet their need for social adjustment. Rather, it resulted in a *conflict with own cultural norms* (Horne et al. 2013). Fasting during the month of Ramadan could become a barrier to physical activities and some Muslim women felt disturbed if they were offered a program that had no gender segregation.

> I was given 'Fitness for Life' by the Doctor … I asked a friend … She said it was a mixed session and told me about X [AgeingWell Co-ordinator] because I didn't want to exercise in mixed sessions. (Horne et al. 2013)

4.3.3.3 Unconventionality

Non-observance of rules for healthy living, however, was not always associated with feelings of disappointment. Older person also had a desire for unconventionality and felt restricted if they should adjust to social norms in an exaggerated way. There were those who did not refuse totally to comply with health-related recommendations but were inclined to *some neglect of rules and regulations* (Graham and Connelly 2013; Menichetti and Graffigna 2016; Boggatz and Meinhart 2017).

> I do exercise, I don't go to a gym … I don't like them. I use the stairs more often … We'll take [our dog] and go to the beaches and do the walk thing … [The gym] is too regimented for me. I just don't like that you've got to be there at eleven and someone tells you what to do; and I'm just not that kind of person… (Graham and Connelly 2013)

Others were even more inclined to an *unconventional way of ageing* (Wang et al. 2001; Leavy and Aberg 2010; Price et al. 2011; Menichetti and Graffigna 2016; Boggatz and Meinhart 2017). They disliked the idea of being physically active just because there was a social norm that forced older persons into active ageing. Instead, they wanted to grow old in a natural way, free of rules and regulations.

> Old people should be allowed to be old and to do their everyday things. They have driven this thing with gyms and strength training so much that I think they have almost gone too far. (Leavy and Aberg 2010)

> Allow people to be old. We get worn out, we all die, that's a fact! But seize the day and take things for what they are. Later life is so restricted, even if you reach the age of 70. But people wouldn't dare to voice that nowadays, they have to be physically active, they have to be healthy, and they have to stay beautiful right up until they die […] If you are old, well then you should be grateful that you can get out of bed and go outside and eat a nice meal and enjoy other people company, enjoy those things instead of constantly chasing after something that is beyond. Live your life here and now. There are a lot of people who don't allow themselves to do that. (Leavy and Aberg 2010)

Such opposition to norms of healthy and successful ageing was a motive behind the above-mentioned negligence towards health. When older persons *disregarded advices* of health care providers they just wanted to follow their own way of life and felt more comfortable if they made no efforts to comply. This was the case, for example, when they were expected to wear anti slip socks to prevent falls.

> I told her I was going to do it [wear my own socks] anyhow and I did. I don't mind people tell me what to do, but I'm not accustomed to it… she wasn't rude about it…I just didn't want to do it. (Miller 2010)

4.3.3.4 Satisfaction of Unconventionality

The desire for unconventionality was obviously satisfied if older persons could live what they felt to be their *own way of life*—unrestrained by regulations (Söderhamn 1998; Söderhamn et al. 2011). This allowed them to enjoy the freedom they had gained after their retirement. One older man described his feelings in the following way:

> The summer was lovely warm and nice. I packed the picnic basket and went to the beach. I visited good friends and had a very good time. (Söderhamn 1998)

Satisfaction of unconventionality did not necessarily preclude participation in health promoting activities. However, what mattered for the older persons was that such participation was not associated with undue restrictions of their liberty. If the latter was the case, older persons *felt constrained by time schedules and regulations* that eventually led to the abandonment of their participation (Nielsen et al. 2014). The same was true for some older peoples' compliance with medical appointments

(Lees et al. 2005). A further factor that affected only older men was that most participants of health promotion programs were women who automatically influenced the programs' social climate with their female habits. As a consequence, male participants could not act to their own habits and *felt restricted by female dominance* (Hutton et al. 2000; Patzelt et al. 2016). Although they did not precisely describe what was alienating them, participants of a focus group discussion made clear that men were rather discouraged to join.

> Since there are usually 99.9% women, men find it very difficult [to participate]. (Patzelt et al. 2016)

4.3.4 Closeness Versus Distance

4.3.4.1 Closeness

Health promoting behaviour of older adults was also influenced by their desire for closeness and social contacts. Since most activity programs were group-based participation depended on the older persons' need for social relationships and on the extent to which this need was satisfied. As described in the previous chapter older persons had an apparent *desire to socialize* (Söderhamn 1998; Wang et al. 2001; Belza et al. 2004; Collins et al. 2004; Berlin Hallrup et al. 2009; Leavy and Aberg 2010; Söderhamn et al. 2011; Brännström et al. 2013; Graham and Connelly 2013; Söderhamn et al. 2013: Patzelt et al. 2016; Lette et al. 2017; Bredland et al. 2018).

> It is very important to have friends … If you do not have a social network, it is not easy to live … I am visiting a man who is alone. He likes me visiting him, and I like to visit him. (Söderhamn et al. 2013)

Health promoting activities were also expected to have a socializing effect and to increase social well-being. Women in particular associated health with social participation (Patzelt et al. 2016). It was this desire that made many older persons join exercise groups. *To become an integrated group member* even seemed to be more important than their intention to promote their health (Hutton et al. 2000; Belza et al. 2004; Price et al. 2011; Boggatz 2011; Nielsen et al. 2014; Patzelt et al. 2016; Boggatz and Meinhart 2017). What program developers may have seen as a positive side effect turned out to be the most important pull factor for participants.

> We should go among people […] and reach out to people. Yes, Go and entertain… to form small groups, to go jogging or to make handicrafts, so, at least not remain alone, but to join a group somewhere(Patzelt et al. 2016)

> It's really important for us in the world to have a safe, healthy community and that's what really helps to come to my exercise classes. I'm excited to see everybody and hear what they have to say and share maybe a little bit of me too. (Price et al. 2011)

As the last statement suggests, social contacts were not only a central motive for participation in group activities, they were also the source of encouragement that gave group members a feeling of being cared for. Some older persons had an explicit *desire for contact with younger persons* since these contacts motivated them to stay active.

> Many people our own age often are unwell, and talk about illness and problems. Such negative talk can easily make you quite depressed. The younger ones do in contrast talk about other things, such as family, home making and leisure activities (Bredland et al. 2018)

As this quotation suggests, social contacts with peers can also have negative impact on the motivation to stay active and to promote one's health. This was also the case if older persons *maintained relationships with unsportsmanlike friends*.

> I have friends I used to work with and we get together. They can keep me from exercising (Lees et al. 2005)

4.3.4.2 Satisfaction of Closeness

The desire for closeness was satisfied when older persons *gained social contacts* through their participation in activity groups. It enabled them to maintain old contacts, make new friends, and enjoy their time together (Frenn 1996; Maddox 1999: Hutton et al. 2000; Miller and Iris 2002; Belza et al. 2004; Morris Docker 2006; Hardy and Grogan 2009; Mathews et al. 2010; Costello et al. 2011; Dickinson et al. 2011; Price et al. 2011; Söderhamn et al. 2011; Graham and Connelly 2013; Li et al. 2013; Nielsen et al. 2014; Barenfeld et al. 2015; Stevens et al. 2015; Patzelt et al. 2016; Komatsu et al. 2017).

> I think these centres are great because we get to talk to other people, even if it is just for an hour. (Frenn 1996)

> We were 16 persons that walked the pilgrim tour. They were very nice people, and we had a pleasant time … and when you know them, you can totally relax. (Söderhamn et al. 2013)

> You don't have as many friends as before, they don't call so often anymore, so you kind of have to pull yourself up and exercise is a good way to do that. Especially because these guys here become your new friends; they replace the ones I've lost (Nielsen et al. 2014)

By joining a group, they could build *social bonds* with other group members they were attracted to, and it were these bonds that encouraged them to continue and ensured their discipline.

> I go to the gym with somebody and that's always nice, you know, to have somebody to encourage you even if you don't feel like going. (Graham and Connelly 2013)

In the same way, older persons established sometimes *positive relationships with their instructor* that gave them a feeling of being cared for and encouraged their participation (Hutton et al. 2000; Horne et al. 2010).

> If you get somebody pleasant [instructor] you know, it does make a difference as well… If you had a bad instructor that was a bit well, not a nice personality… it would put you off. (Horne et al. 2010)

On the other hand, there were also older persons who suffered from a *lack of social contacts* (Leavy and Aberg 2010: Lette et al. 2017). Due to ailments and functional limitations they were not able to go out and participate in group activities. Their inability to promote their health was also an inability to satisfy their need for social contacts. Others were still able to exercise, but they had *no partner* with whom to engage in physical activities (Belza et al. 2004; Boggatz 2011). Since their social needs remained unsatisfied they had no motivation to spent efforts in exercising. But also group membership was not always supportive. Some groups had a social climate that did not suit everybody. If older persons felt that they did not fit into a group they had *no sense of belonging* and gave up both membership and exercising (Belza et al. 2004; Barenfeld et al. 2015). This happened because of differences in age or interests.

> Yes, I suppose it was partly due to the fact that they were all 70 years old, and that I was so much older. And then I thought they were the sort that played golf and [coughs] went fishing and [did] all sorts of things. (Barenfeld et al. 2015)

4.3.4.3 Distance

Not everybody, however, searched for social contacts. Some older persons showed a *preference for social distance* (Leavy and Aberg 2010; Menichetti and Graffigna 2016). They claimed not to be a “group person”, and said that they were not “fond of those places where people go to find a social life” (Leavy and Aberg 2010). Some were afraid that group members would “hassle” them, whereas others abhorred the idea of being “tied down” by social bonds and thought it would be “a nightmare to be part of a club” (ibid.). If these older person were interested in promoting their health they wanted to do it on their own and had a *desire for private exercise* (Hutton et al. 2000). Likewise there were those who were *deterred by overcrowded events* that tried to advertise health promotion (Boggatz 2011).

There were also those who *separated their desire for exercise from their desire for social contact*. They did not refuse social relationships, but when they trained they were not interested in them. The fitness centre was the place that suited them.

> In the fitness centre it’s like getting on the bus. You work out with the ones who randomly sit next to you. We have no social interaction because there’s not time. You come in, sit on the bike and leave again and don’t talk to anyone. (Nielsen et al. 2014)

4.3.4.4 Satisfaction of Distance

Older people with a preference for social distance were *able to maintain their privacy* by either staying away from group exercises and not exercising at all, or by exercising alone (Hutton et al. 2000) or in an environment that prevented social interaction (Nielsen et al. 2014).

4.3.5 Influencing Factors

The satisfaction of social orientations of action depended on the same internal factors as described above. Functional limitations, visual and hearing impairments could be an obstacle for social participation. In the same way psychological factors such as negative moods, knowledge deficit, or language barriers (when older persons were immigrants) could have a negative impact on the participation in group exercises. But also external circumstances played a role. Beside the availability of information, facilities and finances—as mentioned above—social network, organizational matters, quality of care, and features of the social environment were important.

As we saw in the previous section, public information by the media was a prerequisite for participation in health promotion. Advertisements in the newspaper or television made knowledge available in the community. More important for the diffusion of information was the older persons' *social network*. Family (mainly the own children) and friends were a major source of information about available activities and programs (Shearer and Fleury 2006; Dickinson et al. 2011; McGrath et al. 2016; Patzelt et al. 2016; Lette et al. 2017). However, they did not just inform older persons. Their encouragement moved them to action, and made them join and continue a health promoting activity (Hutton et al. 2000; Miller and Iris 2002; Belza et al. 2004; Boggatz 2011; Costello et al. 2011; Price et al. 2011; Horne et al. 2013; Li et al. 2013; Bethancourt et al. 2014; Barenfeld et al. 2017; Boggatz and Meinhart 2017)

> Through a friend who has done it for years and is a right bossy lady and she said 'you should go' so I thought I'd give it a try. (Dickinson et al. 2011)

> It's nice to have a friend, because if you don't feel like going, she might say something to encourage you. Or she might be after you so much that you say, 'Oh, yeah, I'll go.' And you feel so much better afterwards. Believe me. (Belza et al. 2004)

Such encouragement satisfied several orientations of action at the same time. It gave older persons a feeling of closeness and being cared for and allowed them adjusting to social expectations. Some programs used peer mentors to achieve this effect (Horne et al. 2010; Stevens et al. 2015). These were older persons of the same age who had received a short training course that enabled them to encourage and advice others who should be motivated to do home-based exercises. Sometimes general practitioners fulfilled a similar function when they informed and encouraged older persons (Horne et al. 2013; Janssen and Stube 2014). If there was no information available in the social network, it was tiring for older persons to find it.

> You have to ask. You have to be forward. They won't come to you. Yes, nobody's going to come into you personally. (McGrath et al. 2016)

Lack of encouragement from peers could result in abandoning health promoting activities:

> In the beginning I had a female friend here… we were out and… she had a walker too and we could walk as far as the woods… ! But now she's dead like all old folks… and then… I don't have the strength walking so far any longer. (Brännström et al. 2013)

The satisfaction of social needs was also influenced by the *organizational matters.* Discouragement occurred when a fixed program to promote physical activity came to an end and participants lost their contact and were left alone to continue exercising (Dickinson et al. 2011). The timing of exercises was another issue. Older persons preferred to attend programs at daytime because they disliked to go out in the evening (Dickinson et al. 2011). In some cases older persons felt restricted by bureaucracy (Patzelt et al. 2016: Barenfeld et al. 2017), for example, if they wanted to get support from their health insurance to purchase an assistive device.

> I thought it was plus-minus nothing. I thought it was only a huge fight to get a damned, er, bath board! Why can't it be like it was, when I had it before, and I come back with it broken. Why can't I replace it without any fuss. It's the lack of flexibility in the small things that I think is missing, that's what I reckon. (Barenfeld et al. 2017)

Such instances limited older persons' independence and gave them a feeling of not being cared for.

Beside these organizational issues the *quality of care* older persons received from physicians and trainers had a crucial impact on the satisfaction of their social needs. Medical doctors who had no time to listen or to give advice gave them a feeling of not being cared for (Patzelt et al. 2016). Occasional advices provided during a medical check-up or consultation could have the opposite effect.

> I'm diabetic and I started staggering around earlier this year, round about May. And I saw the doctor and the doctor recommended me to go to the Falls Clinic and I have had some benefit from it really. (Dickinson et al. 2011)

Regarding exercise programs it was important that these were designed according to the abilities of the participants (Hardy and Grogan 2009; Mathews et al. 2010; Costello et al. 2011; Dickinson et al. 2011; Li et al. 2013; Janssen and Stube 2014; Boggatz and Meinhart 2017). This gave them a sense of security and promoted in the long run their self-efficacy in exercising. The composition of the training group played a key role as trainers were able to adapt their instructions to an average level of ability and older persons did not feel that they annoyed others with their physical limitations.

> Well I don't know. I think if you're in a mixed age group you might feel a bit more embarrassed about not being able to do some of the exercises and it's probably better to be in a more or less of our own age group and you can all struggle together sort of thing. (Dickinson et al. 2011)

Encouragement by the trainer in a non-authoritarian way (Miller and Iris 2002; Costello et al. 2011) was another important aspect that responded to older persons' need of security and being cared for without restricting independency.

> But it is essential that I have the help of the staff in guiding me; you know if that machine gives you a problem, why don't you try this? (Costello et al. 2011)

Some programs provided the opportunity to monitor the progress achieved in a period of training. Testing their function drew the attention of the participants to their abilities and strengthened their sense of self-efficacy (Barenfeld et al. 2015).

When discussing health issues, an approach was welcome that allowed conversations and reflections because it provided the opportunity to make choices, and gave older persons a feeling of control (Barenfeld et al. 2015).

On the other hand, a uniform training that disregarded individual need, the exertion of pressure, and a top-down approach to instructions without explanations had an intimidating and discouraging character (Miller 2010; Horne et al. 2013). It ignored older persons need for exerting influence on others and gave them a feeling of not being cared for.

Features of the social environment had also some influence on the satisfaction of social needs. If elderly people lived in an unsafe area where they were afraid of crime, they could not meet their desire for security and they abstained from outdoor activities (Belza et al. 2004; Costello et al. 2011; Horne et al. 2013).

4.3.6 Behavioural and Attitudinal Reactions

The behavioural and attitudinal reactions that older persons showed in order to meet their social needs also shaped the way how they promoted their health. By *participation in group activities* older persons could satisfy their need for social contacts. At the same time they reinforced the tendency to social adjustment since they were held at regular times and participation required a sense of obligation. For others, however, such an obligation was an impediment to their desire for unconventionality, as group exercises restricted the liberty to dispose of their time. (Nielsen et al. 2014). Older persons with a need for unconventionality or a need for distance preferred *home-based exercises* (Stevens et al. 2015) or visited a *fitness studio* (Nielsen et al. 2014). In both of these cases, they were able to engage in physical activity without being bound by social ties and restricted by norms that governed groups.

When older people were unable to satisfy their desire for self-reliance, they began to *accept their limitations*. Other older persons who wanted to remain independent as much as possible resorted to *resilience* which was motivated by the desire to maintain self-reliance. Both attitudinal reactions were the same that older persons showed if they were unable to satisfy their desire for physical activity—as mentioned above in the previous section.

4.4 Health Promotion and Identity-Related Orientations of Action

Health promotion did not only have an impact on social orientations of action, it also influenced older persons' identity by either supporting or impeding their identity-related needs. How older people promoted their health depended on how they shaped their identity and their life. The satisfaction of identity-related orientations of action was not simply a further prerequisite for health, for many older people it was rather a manifestation of health itself. In other words, the appropriate balance between work and relaxation, diversion and reflection, concern for others and self-interest, self-presentation and self-concealment, and a positive as well as critical self-perception were attributes of a healthy life that resulted in a sustained state of health. Table 4.5 provides an overview over the aspects of the identity-related orientations of action, their satisfaction or disruption through health promotion or disease prevention, the influencing factors, and the behavioural and attitudinal reactions of the older persons.

Table 4.5 Identity-related orientations of action, influencing factors, behavioural and attitudinal reactions

Orientations of action and their satisfaction	
Work	Desire for meaningful activity
	Work as a suitable means of overcoming diseases
	Work more important than physical exercise
	Disliking exercises as an end in themselves
Satisfaction of work	Fulfilment through activities
	Bored by meaningless physical exercises
Relaxation	Take a break and relax
	Desire to be lazy
Satisfaction of relaxation	Stress reduction and mental relaxation
	Enjoyment of nature
Diversion	Searching for entertainment
Satisfaction of diversion	Having fun and entertainment
	Lack of entertainment when performing exercises
Reflection	Desire for cognitive integrity
	Physically active out of a desire for reflection
	Intellectual interest in health promotion
Satisfaction of reflection	Improved mental fitness
	Intellectual satisfaction
	Exercises appear to be trivial
Concern for others	Desire to be needed
	Concern for others instead of an interest in health promotion
	Supporting others in promoting their health
	Desire to contribute to a team
Satisfaction of concern for others	Having done something for others
	Feeling useful as peer mentor
Self-centredness	Doing something for themselves
Satisfaction of self-centredness	Feeling rewarded for efforts
	Duties prevented the desired participation in health promoting activities
Self-presentation	Leaving a positive impression on others
	Desire to be respected

(continued)

Table 4.5 (continued)

Satisfaction of self-presentation	Feeling of being valued
	Sense of equality
	Stigmatized when needing a walker
	Feeling degraded
	Social exclusion
Self-concealment	Preferring to go unnoticed
	Fear of attracting the attention of others because of physical limitations
Satisfaction of self-concealment	Feeling of annoying others
Positive self-perception	Need to maintain a positive self-image
	Gaining a sense of achievement
	Downward comparisons
	Reminiscence
Satisfaction of positive-self-perception	Positive memories
	Self-acceptance despite limitations
	Experiencing own competence
	Achieving self-imposed goals
	Feeling superior to others
	Feeling ridiculous
	Feeling inferior to others
Critical self-perception	Adjusting self-image to real abilities
Satisfaction of critical self-perception	Self-acceptance despite limitations
Influencing factors	
Internal factors	*Same as in Table 4.3 under physical condition and psychological factors*
External circumstances	*Same as in Table 4.4 under external circumstances*
Behavioural and attitudinal reactions	*Same as in Table 4.4 under coping with help of activities*

4.4.1 Work Versus Relaxation

4.4.1.1 Work

When older persons were asked what contributed to their health, quite often they expressed a *desire for meaningful activities* (Frenn 1996; Söderhamn 1998; Maddox 1999; Wang et al. 2001; Belza et al. 2004; Söderhamn et al. 2011: Gilbert et al. 2012; Söderhamn et al. 2013; Bredland et al. 2018).

> I think you just have to get up and go or sit down and die. Nobody pushes you to do anything at my age and I think people would say not to do this or that, but that is the wrong attitude. You have to get up and go. (Gilbert et al. 2012)

Activities were meaningful if they were of interest to the older persons, kept them busy and filled their daily routine. This could be housework, gardening, any hobby, or regular work. Most of these activities involved physical efforts and satisfied the body-related need for physical activity. In this way, they promoted physical fitness and health, but older persons did not perform them for the sake of this purpose. They rather worked out of a desire to be busy and to feel that they were achieving some results.

> Even though I am 65 years old, I still work as a newspaper deliverer. Every morning, I wake up very early to get some physical activity. In addition to physical activities, mental activities are required. I need to remember where to deliver the newspaper, where to stop. (Belza et al. 2004)

Older persons were convinced that work and meaningful activity automatically promoted their health and they equated active life with health.

> If you stay active, you don't need a doctor (Frenn 1996)

This idea was a reason why some older person believed that performing everyday activities was sufficient to promote their health. Other older persons were even convinced that demanding activities such as *work was a suitable means of overcoming diseases*.

> I think that if you have satisfaction in your job, you will become healthier. I have a chronic disease, and I think it is very important not to sit down … Then I informed the physician that I was working full time and asked if it was a right choice. OK, you are working … I suspected it, he said, and so he took me off the sick list. (Söderhamn et al. 2013)

Others explained that for them their *work is more important than physical exercise* (Mathews et al. 2010; Costello et al. 2011; Dickinson et al. 2011; Patzelt et al. 2016).

> I don't have time to go exercise because I like to do house chores. (Mathews et al. 2010)

For some older persons, exercises for the purpose of exercising without providing any meaningful result were deprived of meaning. They *disliked exercises as an end in themselves* and preferred other activities they perceived to be more meaningful (Hardy and Grogan 2009; Dickinson et al. 2011; Bethancourt et al. 2014; Bredland et al. 2018).

> I am of the view that I only come in order to be able to do other things that are enjoyable … [I] keep fit to enable me to go walking or gardening or whatever but exercise in itself has no pleasure whatsoever for me. (Hardy and Grogan 2009)

4.4.1.2 Satisfaction of Work

The desire to work was met when older persons found *fulfilment through meaningful activities* (Söderhamn et al. 2011; Bredland et al. 2018). Since these activities involved physical efforts they also contributed to their health. In comparison to physical exercises for the sake of exercising they were perceived to be more meaningful. For example, an older man who liked doing repairs said:

> These types of activities feel more meaningful than exercising in the gym. (Bredland et al. 2018)

Older persons like him felt rather *bored by meaningless physical exercises* (Hardy and Grogan 2009; Leavy and Aberg 2010: Costello et al. 2011; Dickinson et al. 2011; Bredland et al. 2018)

> I don't go to a lot of them [exercise classes] but I have been to some and I've come away and I've thought, what did I learn there except to throw this silly ball. (Dickinson et al. 2011)

4.4.1.3 Relaxation

Just like physical activity, work had to be counterbalanced by relaxation. Some older persons said that it was important to *take a break and relax* since recovering from stress would promote their mental well-being (Belza et al. 2004; Söderhamn et al. 2013). Others told about their *desire to be lazy* sometimes:

> …sometimes a lazy streak comes in there every once in a while. I like to do things but, sometimes I just want to vegetate and do nothing. It's all about attitude. (Gilbert et al. 2012)

4.4.1.4 Satisfaction of Relaxation

As a consequence of mental relaxation, older persons *experienced stress reduction and mental relaxation* (Belza et al. 2004; Morris Docker 2006; Cartwright 2007; Li et al. 2013; Boggatz and Meinhart 2017). This occurred, for example, after having received treatment or after finishing exercises:

> You go home [after Qigong, the author] and feel free… free and it is as if… well, as if I am more relaxed. (Boggatz and Meinhart 2017)

Several times this experience was associated with an *enjoyment of nature* (Frenn 1996; Belza et al. 2004; Leavy and Aberg 2010). Walking helped older persons to promote their mental relaxation when they did so in a quiet way and in a peaceful environment. Tai Chi and Qigong could produce a similar effect.

4.4.2 Diversion Versus Reflection

4.4.2.1 Diversion

When older persons participated in health promoting activities they were not only concerned about fitness and social contacts, they also *searched for entertainment* that gave an additional meaning to their group exercises (Belza et al. 2004; Collins et al. 2004; Gilbert et al. 2012; Li et al. 2013; Nielsen et al. 2014).

> That we are together and have fun together is the essence. It also removes any pressure. You just go because you feel like it (Nielsen et al. 2014)

Entertainment was found in the social interaction during and after exercising. But there was also *stimulation through exercise* itself when music or rhythmical movements were involved allowing older persons to physically express their feelings (Belza et al. 2004; Price et al. 2011; Li et al. 2013). For this reason some older persons preferred to dance as their way of physical exercise. But also other kinds of exercises could show a similar effect. Participants in a fall prevention program, for example, felt attracted by Tai Chi because doing the movements together was like creating a graceful slow dance (Morris Docker 2006).

4.4.2.2 Satisfaction of Diversion

The desire for diversion was satisfied when older persons *had fun and entertainment* during exercising and also beyond (Belza et al. 2004; Resnick et al. 2006; Costello et al. 2011; Graham and Connelly 2013; Nielsen et al. 2014). As group members, for example, they could meet up at external venues, such as birthdays, summer, and Christmas parties, and have drinks together after exercising.

> All of us are happy because there's laughter, storytelling, someone wins, someone loses. When we go home, we sleep soundly because there was laughter, and we played bingo. (Belza et al. 2004)

But also the performance of particular exercises itself was associated with feelings of pleasure and fun (Belza et al. 2004; Morris Docker 2006; Price et al. 2011; Li et al. 2013). Participants in a Tai Chi course, for example, described the esthetical pleasure they derived from the movements they performed together (Morris Docker 2006), while other older persons asserted that "dancing is fun" (Price et al. 2011).

However, having fun together did not always contribute to health promotion. Some older persons who were diabetics described dining out with families and friends as their preferred way of diversion.

> We eat out an awful lot, so that's kind of entertainment for us. When you are retired you can do that. (Graham and Connelly 2013)

Although this kind of pleasure contributed to their entertainment, it is rather unlikely that it also promoted their health. On the other hand, health promotion could also have no entertaining value. Exercising without any further purpose was not only perceived to be meaningless and futile, due to their monotonous character some older persons complained about a *lack of entertainment when they performed exercises* (Lees et al. 2005; Bethancourt et al. 2014; Boggatz and Meinhart 2017) These feelings, however, did not apply equally to all types of physical exercise. One older woman contrasted gymnastics with dancing:

> I have to force myself to go to the gym, I don't have to force myself to dance. (Bethancourt et al. 2014)

4.4.2.3 Reflection

Diversion and entertainment had to be counterbalanced by some degree of reflection. Older person had a fundamental interest in cognitive efforts due to their *desire for cognitive integrity* which was the prerequisite for maintaining their identity. (Miller and Iris 2002; Belza et al. 2004; Mathews et al. 2010; Price et al. 2011; Lorenc et al. 2012; Söderhamn et al. 2013; Patzelt et al. 2016; Komatsu et al. 2017; Lette et al. 2017).

> We need to use all approaches to keep the brain healthy…. This is an issue of all aspects… diet, exercise (Mathews et al. 2010)

> I'm a firm believer in that in order to stay… healthy… I need to be mentally and physically alert… participate in all physical things you are capable of and keep the mind open by studying and keeping abreast of what's happening. (Miller and Iris 2002)

As the last statement suggests, these older people were convinced that their mental integrity was also enhanced by physical activity as the Latin proverb mens sana in corpore sano (a healthy mind in a healthy body) says. Mental engagement involved in physical activities was believed to improve mental fitness. Consequently, they were *physically active out of a desire for reflection* (Morris Docker 2006; Komatsu et al. 2017). Walking, for example, was not just a movement of the body, it also satisfied personal interests as it allowed seeing other things, or just thinking about one's life. Performing exercises required them to pay attention to their movements and strengthened their ability to concentrate.

> I am not just exercising but am constantly focusing on how each exercise affects each part of the body. Once I know which exercise is for which body part, I try to stretch correctly. (Komatsu et al. 2017).

For some older people, cognitive efforts were not just a means to maintain cognitive integrity, but a source of inner satisfaction, and they developed an *intellectual interest in particular health promoting practices*. For example, some of them studied herbal medicine and obtained a profound knowledge about healing plants and their application (Boggatz and Meinhart 2017). Others wanted to understand the philosophy behind Tai Chi and were keen to get such information from their instructors (Morris Docker 2006).

4.4.2.4 Satisfaction of Reflection

Older persons who were eager to meet their desire for reflection through physical activities reported about an *improved mental fitness* (Morris Docker 2006; Lorenc et al. 2012; Komatsu et al. 2017). Participants of a Tai Chi course, for example, said that their concentration and body awareness had improved since they started exercising (Morris Docker 2006). But also other activities that required concentration like piano playing could have this effect (Lorenc et al. 2012). Those who had an intellectual interest in health promotion could derive some *intellectual satisfaction* from the deeper examination of this topic (Boggatz and Meinhart 2017). At the same time, however, intellectual interest could make simple *exercises appear to be trivial*. For this reason, some older persons complained about the constant repetitive practicing of Tai Chi (Morris Docker 2006).

4.4.3 Concern for Others Versus Self-Centredness

Concern for others was a central motive for staying active. Depending on the kind of activity that older persons performed in the interest of others, it was in line with health-related activities or it consumed time that prevented older persons from doing something for their health. The same was true for self-centredness that counterbalanced older persons' concern for others. Both orientations of action could have a direct or an indirect influence on the way how older persons promoted their health.

4.4.3.1 Concern for Others

Older persons wanted to be useful for others and had a *desire to be needed*. Helping their children, grandparenting, or volunteering were common ways to meet this desire (Maddox 1999; Grasser and Craft 2000; Wang et al. 2001; Collins et al. 2004; Shearer and Fleury 2006; van Leuven 2010; Costello et al. 2011; Söderhamn et al. 2011, 2013; Lette et al. 2017; Bredland et al. 2018). At the same time, however, caring for others was believed to increase one's own well-being and in this sense it was a way of health promotion for older adults (Collins et al. 2004).

There was, however, no straightforward relationship between this broad understanding of health promotion and its rather narrow meaning in programs that aimed to promote physical activity and exercise. Some older persons had a *concern for others instead of an interest in health promotion*. They gave a higher priority to their social duties and perceived them to be more meaningful than physical exercise (Hutton et al. 2000; Lees et al. 2005; Boggatz 2011; Costello et al. 2011; Söderhamn et al. 2013; Bredland et al. 2018).

> My day is busy I don't have time to be bored, and it's hard sometimes to coordinate and that's why I had to stop um classes because it was pick-up time to drive out there and (pick-up the grandchildren), so I have trouble trying to fit classes around duties (Hutton et al. 2000)

Sometimes, however, health promotion programs met the desire to be useful by giving older persons opportunities to *support others in promoting their health* (Shearer and Fleury 2006; Stevens et al. 2015; Barenfeld et al. 2017; Komatsu et al. 2017). As we saw in the previous section, peer support encouraged participants and gave them a feeling of being cared for. This provided the chance for other group members to show concern for these participants and their needs.

> If someone is absent, I wonder what happened to him or her because he or she is always present. So, to check on the absent person, I call him/her on the way home (Komatsu et al. 2017)

Some older persons also advised non-participating friends to care for their health according to what they had learned in the health promotion program.

> There must be something [to do], I thought when I saw him walking. You have to remember that the foot is bad, but your thighs, you're losing your thigh muscles. What would happen if you couldn't get to that physiotherapist? I think he was at the physiotherapist a few times […] he's been going there all winter, he still goes and he thinks it's good. (Barenfeld et al. 2017)

Some health promotion programs provided a specific framework for such concern for others by engaging and training older persons as peer mentors who visited mentees at home and encouraged them to exercise (Stevens et al. 2015).

Participation in a health promotion program was also consistent with a concern for others if older people had a *desire to contribute to a team*. For these older persons, participation was not just a matter of social adjustment; it had a deeper meaning because they shared a goal with others who depended on their effort. This was, for example, the case when they were members in a football team and wanted to win a match (Nielsen et al. 2014) or when they had to perform dances or exercises in front of a public audience (Resnick et al. 2006).

> We had to do the Cha Cha Slide at the Senior Center Ceremony. We had a goal. (Resnick et al. 2006)

4.4.3.2 Satisfaction of Concern for Others

Concern for others yielded an intrinsic satisfaction. It gave older persons the feeling of *having done something for others* (Costello et al. 2011; Söderhamn et al. 2011: Graham and Connelly 2013; Menichetti and Graffigna 2016; Bredland et al. 2018). One study participant described this benefit as “the fact that you are able to do more things, it allows you to help other people which is really key to being happy” (Costello et al. 2011). Since showing concern for others was a way to promote one’s health, the ability to care for them was a sign of being healthy.

> It makes me feel good to know I have helped somebody. (Collins et al. 2004)

> (Being healthy means) I can do extra for other people. (ibid.)

Encouraging and advising others in their health promotion could yield such a satisfaction. In particular, older persons *felt useful as peer mentors* (Stevens et al. 2015).

Not every older person could show his or her concern for others. Some complained about *feeling useless* and this had a negative impact on their health and well-being.

> Well, it’s just that people, you’re not interesting anymore […] I mean, it’s probably just the feeling one gets, it’s probably not the reality, but the feeling that you’re no longer of interest to anyone anymore. (Lette et al. 2017)

4.4.3.3 Self-Centredness

Concern for others had to be counterbalanced by self-interest if it was not to result in self-neglect. Older persons wanted *to do something for themselves* (Collins et al. 2004; Leavy and Aberg 2010; Söderhamn et al. 2011). This could be time spent to relax or an activity that provided personal pleasure such as dressing up in new clothes, going to the hairdresser, or having a pedicure. Taking up physical activities to enjoy the time could have the same effect. An older woman described how this helped her to discover her own needs and to promote her well-being and health:

> I had nine children, so when my youngest was 10 I realized that I was ready to do something for myself […] Up until then, I didn’t think about myself, so it’s a whole new life opened up for me. (Leavy and Aberg 2010)

4.4.3.4 Satisfaction of Self-Centredness

As the quotation above suggests, exercising could provide an intrinsic satisfaction of self-interest. Self-interest was also met when older persons *felt rewarded for their efforts* spent on exercising.

> We are not in the labour market any longer and the exercise is perhaps a bit like doing a job. We come in an hour a week and do our job and get the reward for it. Not being paid as such, but a different kind of reward. (Nielsen et al. 2014)

Although such reward could simply consist of a feeling of having achieved something, trainers sometimes reinforced it by giving incentive gifts to participants after successful training (Resnick et al. 2006). Sometimes, however, other *duties prevented the desired participation in health promoting activities* (Belza et al. 2004; Horne et al. 2013).

> This is the only day that I get to do something for myself. I always really try, but I have missed [exercise class]. I did miss because mum was sick … I had to go live with her so like I couldn't come here. (Horne et al. 2013)

But also the other way around, health promotion could become a duty that interfered with older persons' self-interest. Those who were more inclined to relax and enjoy their time with entertainment were unlikely to join a training program. Due to their absence they had no reason to complain about restrictions of self-interest through health promotion.

4.4.4 Self-Presentation Versus Self-Concealment

To some extent, health promotion was also a matter of self-presentation and getting the attention of others. Such attention, however, could also reveal aspects of their personality older persons preferred to remain unnoticed. For this reason, they also had tendency to conceal aspects of their self. Since health promotion occurred in groups and in public spaces, it had implications for both orientations of action.

4.4.4.1 Self-Presentation

For some older persons health promotion was associated with a desire to *leave a positive impression on others* in order to attract their attention (Li et al. 2013; Bredland et al. 2018). Weight control, for example, was in some cases not only motivated by an adjustment to social norms but by a desire for having an attractive appearance (Li et al. 2013). Others used the outfit required for physical exercise as a sign of their fitness to impress others. Some older men told how Nordic walking poles served this purpose:

> Poles are associated with sport and with younger people, not with old age. (Bredland et al. 2018)

But also those who were less inclined to self-presentation had nevertheless a *desire to be respected* and to get their due attention (Patzelt et al. 2016; Lette et al. 2017).

> Feeling like you're part of it [society], but also being treated with respect. Because we older people shouldn't get the idea that we don't matter anymore and that we're nothing but a nuisance. And that's the way many elderly feel right now. (Lette et al. 2017)

Being treated in a respectful manner was a precondition for any participation in a health promotion program. Respectful treatment was of course determined by cultural standards. Participants in German focus groups, for example, explained that older persons had to be targeted by mailings in which they were personally addressed. Such a personalized mailing had to be sent in a sealed envelope and also to be addressed to their spouse, if appropriate (Patzelt et al. 2016).

4.4.4.2 Satisfaction of Self-Presentation

Older persons felt respected from others when they had a *feeling of being valued* and treated in a person-centred way that allowed them to voice their opinions.

> They have lots of old people in and they check them and various things but they also make them feel that they're worth something and it's pretty awful being old really. (Dickinson et al. 2011)

Quite often, friends were able to convey this feeling even when older persons were losing their health, their abilities, and their self-esteem (Shearer and Fleury 2006).

Attention and acceptance by others was also experienced when a group they had joined for activities conveyed a *sense of equality*. This meant that there was no distinction between rich and poor (Belza et al. 2004), or between locals and immigrants (Barenfeld et al. 2015)

> But at the same time I feel a bit [laughs], and not just because I moved to Sweden, a bit left out. I have my background from Finland and my situation, from the war and everything. So that [short pause], yes, I thought, that now, isn't it good that they want us to feel well. Just as good as the Swedes (Barenfeld et al. 2015)

Homogeneous group regarding social status or ethnicity were of course more likely to create this feeling. Several times, however, health promotion did not result in the acceptance of others. Some older persons complained about *being stigmatized when needing a walker* (Berlin Hallrup et al. 2009; Brännström et al. 2013). They felt ignored and some reported with indignation about the disrespectful treatment by others because they had an unsteady gait.

> Well it's just that some have said 'no, one shouldn't have a walker…no' and they said that to me!! (Brännström et al. 2013).

Others *felt degraded* by the disrespectful behaviour of an instructor. As one participant of a fall prevention program told: "They treated me like I had Alzheimer's" (Miller 2010).

Others older persons reported about *social exclusion* (Janssen and Stube 2014; Nielsen et al. 2014). They were prevented from joining sports associations due to their being too old and felt alienated from the "youthful" fitness culture prevailing in fitness studios.

> The older you get, the harder it is to get in. Imagine being 60 and wanting to play some football; who wants to play football with someone who's 60? (Nielsen et al. 2014)

4.4.4.3 Self-Concealment

The tendency to self-presentation had to be counterbalanced by a tendency to self-concealment since older persons did not want to attract undesired attention. They *preferred to go unnoticed* especially since they feared that their weaknesses would become apparent. For this reason, some were reluctant to use assistive devices like a walker that made such weakness visible (Miller 2010; Brännström et al. 2013; Bredland et al. 2018).

> You don't want to be old and it is by preference not to be seen. (Brännström et al. 2013)

In a similar way, others disliked to join exercise groups out of *fear of attracting the attention of others because of their limitations* (Costello et al. 2011; Bethancourt et al. 2014). They believed that their disability would slow the class down and cause the group to wait for them. They were afraid to attract negative attention and become a nuisance to others.

> They have a walking group, and I haven't joined because I figure I won't go as fast as they go, and so I wouldn't be able to keep up. (Costello et al. 2011)

Needless to say that such negative attention from others could easily result in feelings of shame since older persons could not meet the expected standards of such activity groups.

4.4.4.4 Satisfaction of Self-Concealment

Older persons who avoided attracting the attention of others were satisfied when their weaknesses or disabilities remained unnoticed. However, if they participated in exercise groups despite limited abilities they had a *feeling of annoying others* with their disabilities (Costello et al. 2011). Using a walker in public places in order to prevent falls could result in similar feelings, because these older persons needed a larger space and a place for parking the vehicle. Because walkers could become an obstacle for other persons they were worried about creating an undue public disturbance (Brännström et al. 2013).

4.4.5 Positive Versus Critical Self-Perception

Health-related behaviour was also influenced by the positive and critical self-perceptions of older persons. Whereas positive self-perception was a source of encouragement, critical self-perceptions could have the opposite effect. The performance of health-related activities could have in turn an influence on the way how older persons perceived themselves.

4.4.5.1 Positive Self-Perception

Older persons were not only concerned about doing something for themselves; they also had a *need to maintain a positive self-image* (Maddox 1999; Wang et al. 2001; Miller 2010; Li et al. 2013). For this reason, they rejected anything that did not correspond to this image. Walking aids, for example, could be a sign of unwanted frailty, and hence they were avoided:

> Everybody wants me to go on a walker…and pride gets in your way, you know…I didn't want to use those walkers. I don't need something like a crutch…I can still do it on my own (Miller 2010)

Maintaining a positive self-image could be in line with concern for others when older persons derived confidence from a feeling of being needed, but it could also be consistent with self-interest. Some older persons, for example, were eager to *gain a sense of achievement* through exercising in order to improve their self-image (Resnick et al. 2006; Nielsen et al. 2014; Patzelt et al. 2016; Boggatz and Meinhart 2017).

> We were each looking forward to different things [goals]–some wanted to get stronger and some wanted to lose weight (Resnick et al. 2006)

Some of these older persons became a member of a football team (Nielsen et al. 2014), others were committed to regular individual activities like mountaineering or skiing to obtain a sense of achievement (Boggatz and Meinhart 2017). Older men in particular perceived exercising as a challenge that allowed testing one's limits and having success (Patzelt et al. 2016). Overdoing physical efforts could contribute to establishing a positive self-image in comparison with others:

> In my mind I am still 30 years old, and when I see others walking fast or working hard I want to be as good, or even better than them. (Bredland et al. 2018)

This attitude was sometimes beneficial for health, but it could also be detrimental as one older man admitted when he claimed that by practising sports he had done "everything that had ruined his body" (Boggatz and Meinhart 2017).

These attempts obtain a positive self-image were associated with a desire to impress others and to gain their attention. Others were the frame of reference for self-perception, and their acknowledgement satisfied the need for a positive self-image. Other older persons maintained a positive self-image although they were unable to impress on others. When they experienced a decline of abilities they resorted to *downward comparisons*. Paying attention to others who were worse off allowed them to feel relatively better (Brännström et al. 2013; Cartwright 2007). Others did not even pay attention to people around them at all in order to obtain a positive self-perception. By *reminiscence* they were able to maintain a positive self-image, so that they did not need any further experiences of success (Brännström et al. 2013; Söderhamn et al. 2013).

4.4.5.2 Satisfaction of Positive Self-Perception

The desire for a positive self-perception was met when older persons felt that they had *mastered a challenge* (Morris Docker 2006; Nielsen et al. 2014; Boggatz and Meinhart 2017). Some of them described the satisfaction they derived from learning the movements of Tai Chi which required concentration and memory. Others told that they were motivated to play football when they succeeded in applying a strategy as a team that yielded a positive result.

> It's important to score goals, it's not important to win. (Nielsen et al. 2014)

Experiencing their own competence by mastering everyday activities or helping others promoted of course a positive self-image (Söderhamn 1998; Söderhamn et al. 2011; Bredland et al. 2018). *Achieving self-imposed goals* when doing sports or exercising had the same effect (Hutton et al. 2000; Resnick et al. 2006; Li et al. 2013; Nielsen et al. 2014; Barenfeld et al. 2015; Patzelt et al. 2016: Boggatz and Meinhart 2017)

> I had to prove to myself that I could do it. It was a bit challenging and scary but I did it! I overcame the fear of exercising just by doing it. (Resnick et al. 2006)

In all these cases, a gain of self-efficacy was associated with a feeling of pride and self-esteem that gave a deeper meaning to the desire for self-reliance that has been discussed in the previous section. Some older persons gained pride because they perceived exercising as a kind of competition that they could win. For others successful participation in exercises was enough to *feel superior to others*—even to younger persons (Hutton et al. 2000; Cartwright 2007; Hardy and Grogan 2009; Brännström et al. 2013; Nielsen et al. 2014; Bredland et al. 2018).

> I thought it was exciting, challenging … the challenge was to be better than the others, but deep down you were competing against yourself (Nielsen et al. 2014)

> We went through perhaps harder times and are perhaps more determined and stoic whereas younger people tend to give up a little bit too easily. (Hardy and Grogan 2009)

Older person who experienced physical decline could obtain feelings of superiority by downward comparisons with those who were worse off:

> I can still get about. When you see people in wheelchairs and sticks, I don't have any of those problems, touch wood, so I would say on the whole I can't complain (Cartwright 2007)

There were, however, also exercises that had a negative influence on self-perception. Jumping as a high impact physical activity to promote bone health in the case of osteoporosis made some older persons *feel ridiculous* in their own eyes and was not compatible with their self-image. Furthermore, if older persons were unable to keep up with other group members during exercises they did not only perceive themselves to be a nuisance to others, they also *felt inferior* and suffered as a consequence from lack of self-esteem (Hutton et al. 2000; Belza et al. 2004; Cartwright 2007; Costello et al. 2011; Dickinson et al. 2011; Bethancourt et al. 2014; Patzelt et al. 2016).

4.4.5.3 Critical Self-Perception

The desire to maintain a positive self-perception was counterbalanced by a critical self-awareness. Older persons who felt unable to participate in group activities had realized that they were no longer 30 years old and that they had to *adjust their self-image to their real abilities* unless they wanted to entertain an illusionary idea of themselves (Maddox 1999; Brännström et al. 2013).

4.4.5.4 Satisfaction of Critical Self-Perception

Excessive self-criticism could result in a loss of self-esteem, as we saw in the previous section. However, older people with age-related disabilities, who lowered their expectations to a reasonable extent, were able to experience *self-acceptance despite limitations* (Maddox 1999; Brännström et al. 2013). As one older woman put it:

> I like myself better as I begin to grow up and understand myself. (Maddox 1999)

With such an attitude, dependence on a walker had no negative impact on self-image, as the acceptance of their disabilities made them aware of the benefits of such a device.

> No I didn't find it hard to get used to the walker and I've never felt… there are many people that have feelings of shame… I've never felt that…on the contrary it is… it is one's salvation… (Brännström et al. 2013)

4.4.6 Influencing Factors

In the context of health promotion and disease prevention, the satisfaction of identity-related orientations of action depended on the same external circumstances as social orientations of action. The social network and the quality of care had an either positive or negative impact on older person's self-presentation and self-perception. Encouragement by family, peers, or instructors promoted both, whereas lack of attention to their needs or an authoritarian style in group exercises was likely to show the opposite effect. Furthermore, the way how such exercises were performed could meet the desire for entertainment and diversion or it made older persons feel bored until they gave up participation.

4.4.7 Behavioural and Attitudinal Reactions

In the context of health promotion, behavioural reactions for the satisfaction of identity-related orientations of action were the same as for the satisfaction of body-related needs. Older persons tried to meet their desire to work through a variety of activities like domestic work, gardening, or moving around to accomplish affairs—as mentioned in two sections above. Since these activities involved physical efforts they also had a health promoting effect that was recognized by the older persons. However, this effect was not of central concern for them. It was rather the result that could be achieved through such work that mattered and that made the physical effort involved in it meaningful. It was therefore not surprising that there were those who considered everyday activities to be sufficient to stay healthy and had no interest in physical exercise for the sake of exercise. Those, however, who performed such exercises were motivated by further identity-related needs. Exercising in a group met a desire for diversion, corresponded to a tendency of social adjustment and gave an opportunity to get attention from others and gain their respect. Participation in competitive exercises or just mastering a physical challenge could promote a positive self-image even if it had detrimental effects on health—as it was reported by some men. Walking in the nature, on the other hand, allowed for mental relaxation. Sometimes, alternative methods like Tai Chi or Yoga were chosen out of a similar motivation and could also meet a desire for reflection.

These behavioural responses were of course associated with attitudinal reactions. Resilience that was motivated by the desire for self-reliance also triggered physical efforts older persons made to meet their desire to work and to obtain a positive self-image. Acceptance of age-related limitations corresponded to the tendency of a critical self-perception that allowed older persons to adjust their self-image to their actual abilities. Such an adaptation of self-perception could be compensated by a tendency to think positively which is—as we will see in the following section—a manifestation of the tendency to hope that belongs to the development-related orientations of action.

4.5 Health Promotion and Development-Related Orientations of Action

Health promotion requires to some extent a change of one's life. In some cases, change may be voluntarily initiated out of a desire to learn new things. Health promotion may therefore be motivated by a desire to search for new perspectives. Since, on the other hand, people are also inclined to maintain habits and routines any attempt to induce a behaviour change will also be influenced by this opposite tendency. Growing old is furthermore associated with involuntary change. Frailty implies an increased exposure to health risks. Older persons may respond to such threats by denying or confronting such adversities. Both tendencies will shape their way of health promotion. Finally, if older persons experience a loss of health or become suddenly aware of their health risks, they may remain sceptical about chances of improvement or they may respond with a tendency to hope in order to discover something positive in their negative situation. Both tendencies have of course also an impact on health promotion. As we already mentioned in the previous sections, denial and hope were attitudinal responses of older persons who could not meet their body-related, social or identity-related needs. The examination of development-related needs thus completes the overall picture and shows how the satisfaction of all aforementioned orientations of action is embedded in the satisfaction of the development-related needs. Again, it should be stressed that for many older persons the satisfaction of these needs was not simply a prerequisite for health, but a manifestation of it. Table 4.6 provides an overview over the aspects of development-related orientations of action, their influencing factors, and the behavioural and attitudinal reactions.

Table 4.6 Development-related orientations of action, influencing factors, behavioural and attitudinal reactions

Orientations of action and their satisfaction	
Attachment to the past	Continuing the habitual way of life
	Cultural preferences
Satisfaction of attachment to the past	Preserving an active lifestyle
	Irritated and disturbed by the idea of health promotion
Searching new perspectives	Desire to discover new things
	Being eager to search health information
	Integrating new behaviours into established routines
Satisfaction of searching new perspectives	Gain of knowledge
	Development of new habits
	Temporary change
Denial of adversities	Avoidance to think about health risks and ill-health
Satisfaction of denial of adversities	Being saved from worries about the future
Facing adversities	Proactive awareness of own vulnerability
	Contemplating a change in behaviour
Satisfaction of facing adversities	Potential for action
	Ability to handle limitations
Scepticism	Sceptical about alternative treatments
Satisfaction of scepticism	Protected from disappointment and disillusionment
	Composure
Hope	Thinking positive
	Practicing a religious belief
	Searching a spiritual dimension
Satisfaction of hope	Enjoying life despite limitations
	Inner strength after overcoming a crisis
	Strength in the face of approaching death
	Religious comfort
	Spiritual experiences Feeling of inner balance and harmony
Influencing factors	*(same as under body-related, social, and identity-related orientations of action)*
Behavioural and attitudinal reactions	Alternative ways of health promotion Religious practices *(attitudinal reactions are the same as development-related orientations of action)*

4.5.1 Attachment to the Past Versus Searching New Perspectives

4.5.1.1 Attachment to the Past

In general, older persons wanted to *continue their habitual way of life*. They had a desire to age at home in their own dwelling (Söderhamn et al. 2013; Lette et al. 2017) and wanted to maintain routines they had acquired—as some of them said—since childhood (Frenn 1996; Wang et al. 2001; Janssen and Stube 2014).

> Childhood don't leave you, because it's there, the whole pattern… when you're raised up like that, you don't change it. (Frenn 1996)

Some of them also admitted that they were less eager to develop new habits:

> After all, my life is ok for me, so I do absolutely nothing to change it … I'm fine by myself as well, so I don't really look for particular situations to increase what I should do to feel better. (Menichetti and Graffigna 2016)

Consequently, those who had never been inclined to sports and exercise were less likely to engage in physical activity in old age (Boggatz 2011), whereas those who were used to exercise had developed the habit of a physically active life (Hutton et al. 2000; Leavy and Aberg 2010; Gilbert et al. 2012).

> If you are active when you are young, you'll keep it up for the rest of your life… it's ingrained in you, I don't think that you can change that. (Leavy and Aberg 2010)

If they participated in health promotion programs, the choice of activities was shaped to some extent by *cultural preferences*. Members of the Chinese minority in the UK, for example, explained:

> But I think most Chinese like to learn [Tai Chi] because it's originally Chinese, isn't it? Lots of history to it and many different forms… Like we said, it's more or less our type of exercise. (Dickinson et al. 2011)

Beside those who maintained a habit of physical activity there were also those who had been active and sporty in their youth but were now less inclined to join health promotion programs. They had *abandoned an active lifestyle* because of physical wear and tear.

> I've been working since I was 14 […] I was always fond of work, work never came hard to me, so when I retired I did too much around the house and burnt myself out. (Leavy and Aberg 2010)

4.5.1.2 Satisfaction of Attachment to the Past

Older persons who had a habit of active life were enabled to *preserve their active lifestyle* through participation in health promotion programs (Miller and Iris 2002; Belza et al. 2004; Leavy and Aberg 2010; Mathews et al. 2010; Boggatz 2011;

Graham and Connelly 2013; Bethancourt et al. 2014; Janssen and Stube 2014; Boggatz and Meinhart 2017)

> Going back to my teenage years when everybody was jumping with joy and pleasure about getting involved in jitterbug and ballroom dancing, that was the thing. Everybody did it. My comment now – well, I never left, I'm still jumping. (Miller and Iris 2002)

Those, however, who had never been used to do sports and physical *exercise felt irritated and disturbed by the idea of health promotion* (Boggatz 2011; Graham and Connelly 2013; Horne et al. 2013; Li et al. 2013; Bethancourt et al. 2014). According to them, exercising was unnatural or not decent.

> We did not do any gymnastics at school, we grew up during the war … we did not have gymnastics and now I'm supposed to twist my bones? (Boggatz 2011)

> Some of us ladies were born at a time where girls didn't sweat. (Bethancourt et al. 2014)

Others, however, who would have liked to exercise, complained about the *loss of their active lifestyle* due to age-related limitations.

> It was just getting to me because I was always an active person, and I was just sitting there staring at the walls or the TV, hopping into the kitchen and getting things to eat, I was putting on weight and I was just painful, painful and depressed I think because I couldn't go out. (Cartwright 2007)

4.5.1.3 Searching New Perspectives

To some extent, older persons were not only concerned about preserving their usual way of life; they also had a *desire to discover new things* and learn about ways of health promotion they were not used to—as for example Tai Chi (Morris Docker 2006; Söderhamn et al. 2011). Some even equated the search for new experiences with health promotion and claimed that travelling to see other cultures and meet other people made them feel good (Söderhamn et al. 2011). Other older persons were *eager to search health information* because they had a keen interest in learning about health.

> This spurs me into action. I sit down at the computer, go out on the internet, find literature that I think will be useful to me and I search, expanding what I find [in the content of the printed material] even more. (Barenfeld et al. 2017)

When it was not just about getting to know something new, but about developing new habits, older persons preferred to *integrate new behaviours into established routines*. As one older woman who was expected to perform high impact physical activity to increase bone strength explained:

> I mean it's not that hard, is it, ten jumps every so often. That's something you could do as you're walking around, sort of thing. Every now and again I'll have a go. Once you got into it, I suppose you could do it really just without thinking. (Simmonds et al. 2016)

4.5.1.4 Satisfaction of Searching New Perspectives

Participation in health promotion programs could result in the *gain of knowledge* that created new health awareness (Frenn 1996; Hutton et al. 2000; Resnick et al. 2006; Dickinson et al. 2011; Barenfeld et al. 2015)

> We learned new things about exercise. She [the instructor] helped us know how to do the exercises. She kept doing new things to keep it interesting and kept it fun! She taught us all to take pulses and that was great. (Resnick et al. 2006)

As a consequence, several older persons reported about the *development of new habits* and lifestyle changes (Hutton et al. 2000; Leavy and Aberg 2010; Komatsu et al. 2017). Exercising became a substitute for activities they had performed before retirement and satisfied a desire for change that had been induced by the loss of their life-long occupation.

> After I retired, I was so free that I often tended to get up late. But when I know it's an exercise day, I get up on time and get myself ready. I think it's good for me. (Komatsu et al. 2017)

> The biggest thing of exercise I believe is doing it, the regularity, I do mine every day. It's become a habit If you don't do it you feel something's gone wrong or something's missing. (Hutton et al. 2000)

Others, however, achieved only a *temporary change* (Horne et al. 2010). For them, participation in health promotion was not related to a desire to try out something new. Due to the lack of internal motivation they depended on external encouragement and failed to sustain their activities if such encouragement was missing.

> I mean quite a few years ago I got a referral from the doctors to go to fitness for life, and they stop it. They give you so long and then they stop it. Now perhaps if that had carried on, I might have carried on, but they only gave you so long and then stopped it. (Horne et al. 2010)

4.5.2 Denial of Adversities Versus Facing Adversities

Health promotion was not only influenced by readiness for voluntary change. Older persons had also to deal with risks and adversities that could change their lives against their will. In response, some were rather inclined to a denial of such adversities whereas others tended to face them.

4.5.2.1 Denial of Adversities

Some older persons showed an *avoidance to think about their health risks and ill-health* (Berlin Hallrup et al. 2009; Menichetti and Graffigna 2016; Lette et al. 2017; Bredland et al. 2018). Despite their awareness of their frailty and vulnerability, they disliked to take precautions and tried to continue their life as if there was nothing to worry about. They were afraid of diseases and their consequences, but saw no way to avoid them. The only solution was apparently to ignore them. These older persons remind us of those who avoided consulting a doctor for fear of a diagnosis, as we saw in the previous chapter (Leung et al. 2004). One may assume that such denial was in some cases an underlying motive for the above-mentioned negligence towards health and served as an ineffective coping strategy. When feeling sick they disliked seeing a doctor and even if they had to struggle to maintain an independent life they pretended that everything was fine. As one of them said:

> When I'm sick I avoid to think about this and I do nothing. (Menichetti and Graffigna 2016)

4.5.2.2 Satisfaction of Denial of Adversities

Such non-observance of adversities *saved* older persons *from worries about the future* and allowed them to continue their usual way of life at least for some time (Berlin Hallrup et al. 2009; Menichetti and Graffigna 2016; Lette et al. 2017; Bredland et al. 2018). The investigated studies, however, do not report what happened when they had to give up their denial. We will turn to this issue in the following chapter where we investigate the experience of quality of life in long-term care facilities.

4.5.2.3 Facing Adversities

Other older persons showed a rather *proactive awareness of their vulnerability* (Wang et al. 2001; Brännström et al. 2013). They discussed health risks, the possibility of becoming care dependent, and even their approaching death with families and friends. Such awareness could be triggered by the experience of critical incidences. This could be a disease they had experienced (Graham and Connelly 2013) or the observance of how others got struck by illness which was described as turning point in their lives (Hardy and Grogan 2009; Price et al. 2011).

> My mother died much younger than I did, both my sisters have died, it's given me a spur to stay fit, to keep my weight down because of joint problems […] it's given me a spur to do as much as I can because to get as much out of life as I can so it was quite a turning point when it happened to me (Hardy and Grogan 2009)

While in some cases risk awareness led older persons to take action, others just *contemplated a change in behaviour* in case it should become necessary (Hutton et al. 2000; Barenfeld et al. 2017).

> I know that I can hold off things, so I think, when I need to. And later on, maybe I start to root around [for more information] if I want to. But not right at the moment. (Barenfeld et al. 2017)

4.5.2.4 Satisfaction of Facing Adversities

A proactive awareness for risks did not necessarily have a discouraging and paralyzing effect. In a healthy extent it could rather trigger a *potential for action* as the quotation above suggests, where a critical incidence became a turning point in the older persons' life (Hardy and Grogan 2009; Price et al. 2011; Graham and Connelly 2013). If older persons already had to cope with disabilities an awareness of risks reinforced their tendency to protect their physical integrity and by taking precautions they gained *an ability to handle their limitations*. For example, those who were willing to use a walker learned the necessary skills to handle the device and developed new routines that enabled them to minimize their risk for falls (Brännström et al. 2013).

4.5.3 Scepticism Versus Hope

When older persons were confronted with adversities like the loss of their health or functional decline they could resort to scepticism or hope. A sceptical attitude prevented them from illusions about their future perspective and allowed them to accept their given situation, but it could also result in despair. Hope, on the other hand, could promote self-deceptions about future opportunities, but it allowed also discovering something positive in a negative situation.

4.5.3.1 Scepticism

The experience of illness triggered of course a desire to be cured. Some older persons, however, did not believe in the effect of every available treatment option. They rather remained *sceptical about alternative treatments*. For them, alleged effects of such treatments were rather miraculous and just a result of wishful thinking. One of them told about his mistrust in homeopathy.

> Something I've always, not despised, but thought ludicrous, where you dilute and dilute and dilute. (Lorenc et al. 2012)

Another one criticized reflexology for similar reasons:

> The science of reflexology, which I just cannot tolerate, that rubbing your big toe for instance will cure a headache. As a logical person, which I hope I am, I just cannot accept. (ibid.)

According to them, health promotion should not be based on belief but on empirical evidence.

4.5.3.2 Satisfaction of Scepticism

Scepticism about alternative treatments *protected* older persons *from disappointment and disillusionment* (Lorenc et al. 2012). A sceptical attitude also allowed for a realistic assessment of possibilities and prepared older persons to accept a decline of health. They learned to perceive ageing as a normal process and to endure diseases with *composure* which enabled them to accept their limitations (Söderhamn 1998; Wang et al. 2001; Menichetti and Graffigna 2016). As an older woman put it:

> The problem is not to avoid diseases but to live with them in a decent way and in line with your life. (Menichetti and Graffigna 2016)

4.5.3.3 Hope

Scepticism had to be counterbalanced by some degree of hope in order to find life still worth living in the face of adversities. The most common way to find something positive in a negative situation was to *think positively* (Maddox 1999; Grasser and Craft 2000; Miller and Iris 2002; Collins et al. 2004; Cartwright 2007; Söderhamn et al. 2011, 2013; Gilbert et al. 2012; Patzelt et al. 2016). This prevented older persons from being depressed and enabled them to continue their life and to promote their health despite their limitations.

> Being healthy is having a positive outlook on life regardless of whether the person has a disability or something else. (Miller and Iris 2002)

> I think the important thing is to be optimistic … to keep believing that you will stay healthy and age in peace and harmony, and that your interests will include other things besides just coping with your illnesses (Patzelt et al. 2016)

Some older persons dealt with health risks and adversities by *practicing a religious belief*. They perceived praying to be a way of health promotion. Health had for them a religious dimension and implied obtaining salvation. As some members of the Hispanic and Afro-American minorities in the USA put it:

> I go to church every day. That's the best medicine.
>
> Prayer and belief in the Lord (make you a healthy person). (Collins et al. 2004)

For some older persons physical exercise to promote their health was directly related to their desire for spiritual devotion.

> When I wake up, the first thing that I do is to pray to God. The second, I exercise. (Belza et al. 2004)

Other older persons did not have an affiliation with an established religion but they *searched for a spiritual dimension* (Morris Docker 2006; Boggatz 2011; Boggatz and Meinhart 2017). According to them health promotion included practices like meditation, Yoga, or Qi Gong. One older woman explained her interest in such practices in the following way:

> These are spiritual things that play a role in it (…) you just get ideas that go beyond the physical. (Boggatz 2011)

Users of alternative treatments were sometimes inclined to search for such a dimension.

4.5.3.4 Satisfaction of Hope

Older persons who were inclined to think positively were able to *enjoy their life despite limitations* since they were able to discover the positive aspects of their condition (Maddox 1999; Grasser and Craft 2000; Miller and Iris 2002; Collins et al. 2004; Cartwright 2007; Leavy and Aberg 2010; Söderhamn et al. 2011, 2013; Gilbert et al. 2012; Patzelt et al. 2016).

> I turn 70 in 2 years, and for example, my shoulder is ruined, I am not as flexible and my knees are very bad… It's actually very nice to relax now. (Leavy and Aberg 2010)

Such an enjoyment despite limitations went beyond a narrow understanding of health as physical fitness. For these older persons, health did not preclude physical limitations. It rather consisted of mental and emotional well-being that enabled them to live with such limitations.

A tendency to hope in the face of a serious disease could furthermore result in an *inner strength after overcoming a crisis* (Söderhamn 1998; Maddox 1999; Söderhamn et al. 2013; Menichetti and Graffigna 2016)

> When I got cancer I thought it through some days. So I was finished with it. I saw on it with a good mood. The more you have gone through, the more it will help for the future. (Söderhamn et al. 2013)

Hope gave these older persons *strength in the face of the approaching death* and health meant for them to expect death with inner peace and calmness.

> Sooner or later life ends. It is important to have the satisfaction of having done something, to have done things, to have left something … more than the fear of death, I'd rather end in a particular way. (Menichetti and Graffigna 2016)

Among older persons who practiced a religious belief such experiences were often associated with a gain of *religious comfort* (Söderhamn 1998; Maddox 1999; Price et al. 2011; Söderhamn et al. 2011, 2013). They were grateful to a superior force for the health they got and trusted in God because—as an older nun put it—they were convinced that he took care for those who are doing his work on earth (Maddox 1999). Another woman explained:

> I mean that we, who are Christians, are very lucky … we do not need to think negative thoughts because we can slough them and get a new start and look forward … Yes, you have to put the future in the hands of God (Söderhamn et al. 2013)

For some of them, a simple activity like walking provided a religious experience:

> It might sound silly, but I walk and pray. When you are in nature, you find yourself grateful to be alive. (Belza et al. 2004)

Those who were in search of a spiritual dimension described sometimes their *spiritual experiences*. An older man, for example, who practised Christian mysticism to overcome his chronic disease told about vision he once had:

> The meditation I just did has an impact on every aspect of my health. It's not simply that my asthma is gone… the energy rises from my toes and it comes with colours and with light. (Boggatz and Meinhart 2017)

From a sceptical point of view, such an experience may be the result of an exaggerated believe in miraculous powers. Unfortunately, the available studies do not provide any information on the extent to which such beliefs have or have not been satisfied on the long run and therefore do not allow any conclusions to be drawn about the credibility of such statements. Older persons who were less inclined to such mysticism just described the result of alternative ways of health promotion like Tai Chi as a *feeling of inner balance and harmony* between body and mind (Morris Docker 2006; Boggatz 2011).

4.5.4 Influencing Factors

As mentioned above, a decline of health could stimulate a readjustment of body-related orientations of actions (Boggatz 2011; Gilbert et al. 2012). The experience of physical limitations led to a change of consciousness, which gave the impetus to face adversities. We also saw that in response to the experience of symptoms, some older people were inclined to avoid diagnosis and treatment (Leung et al. 2004; Berlin Hallrup et al. 2009; Menichetti and Graffigna 2016; Lette et al. 2017; Bredland et al. 2018). Whether older persons were ready to deal with perceived risks for their health and began to search for new perspectives in their life depended of course on external circumstances. These were, as mentioned above, the availability of health promotion programs, a convenient transportation system, a supporting social network, and financial resources. If available and familiar to the older persons, programs that offered alternative ways of health promotion like Tai Chi or Yoga could meet a desire for inner peace and harmony which was a way to find hope and think positive.

4.5.5 Behavioural and Attitudinal Reactions

Practicing such *alternative ways of health promotion* was a way to react to a threat or loss of inner balance. *Religious practices* had the same function. All these behavioural reactions aimed to promote health in a broader and holistic sense that was not restricted to the ideal of physical fitness and functionality. As far physical well-being itself was concerned, development-related orientations of action were at the same time attitudinal reactions to a perceived threat of health. Facing adversities by becoming aware of one's vulnerability could trigger a potential for action, and searching for new perspectives could help to overcome a lack of health-related knowledge and sometimes even the routines of a sedentary lifestyle. A denial of health risks had of course the opposite effect. Thinking positive as an expression of hope could give older persons the inner strength to deal with adversities and help—as some of them said—to overcome crises caused by illness.

4.6 Discussion

This chapter investigated how health promotion and disease prevention interfere with quality of life as it is perceived by older persons. The orientations of action as described in the previous chapter turned out to be a useful framework for understanding their attitudes towards health-related interventions. The only exceptions were sexual desire and sexual abstinence that were not mentioned in any of the investigated studies. Although sexual activity may have a positive effect on health (DeLamater 2012), it is apparently not considered to be of relevance in the context of health promotion. The non-observance of this topic by health promotion programs and older persons may be due to the taboo of sexuality in old age.

Studies investigated in this chapter are likely to have a similar bias of social desirability as studies described in the previous chapter. As explained earlier, this bias is not avoidable because performance of social roles according to the expectations of others is an essential aspect of personhood. Furthermore, if aspects are rarely mentioned, it is because older persons are only partially aware of the habits that shape their way of living and produce their experiences.

It is furthermore noticeable that most health-related programs investigated by the studies in this chapter understand health promotion and disease prevention as a part of individual behaviour. They rarely address health in old age as a responsibility of the society. When asked about their ideas regarding health promotion, older persons nevertheless told about external circumstances that influenced their health behaviour. Unsafe environments, lack of facilities in the vicinity, lack of convenient transportation systems, ageism, and unequal distribution of income that allowed or prevented participation were issues raised by participants. Exercise programs that were implemented under such circumstances had no possibility to change them. Community work with the aim of empowering older persons to control such health-related issues in their community was apparently absent. One investigated program tried at least to involve participants in its design and implementation so that they could influence it within its framework (Patzelt et al. 2016). The prevailing impression, however, was that health promotion was meant to instruct and train older persons in a unidirectional top-down approach. The mismatch between older persons' orientations of action and the aims of such programs that was found in the investigated studies is partly due to this approach.

4.7 Conclusion

As expected, there is no straightforward relationship between the health-related ideas of health professionals and those of older persons. The various ways how health promotion as designed by experts can be in accordance or non-accordance with older persons' orientations of action are shown in Table 4.7.

In some cases, health-related interventions are in accordance with older persons' orientation of action. Exercise programs, for example, may meet their desires for physical activity, closeness, and diversion. Such a fit between orientations of action and health-related interventions depends to some extent on the attitudes of the older persons, but also on the character of the intervention.

There are other cases where the opinion of health experts is in contradiction to the orientations of actions of the older persons. Sometimes such a contradiction may provoke a readjustment of the attitudes and behaviour of the older persons.

Table 4.7 Health promotion and orientations of action

Body-related orientations of action	
Physical activity *In accordance with health promotion* if older persons enjoy physical activity and gain fitness through exercises *Not in accordance with health promotion* if older persons tend to go to their limits and overload their physical capacities	*Physical rest* *In accordance with health promotion* if older persons can recover from physical activities and improve their sleep *Not in accordance with health promotion* if older persons are inclined to comfort and inertia
Body protection and regeneration *In accordance with health promotion* if older persons are careful about their physical integrity, take preventive measures, observe medical treatments, and get advice how to manage unpleasant symptoms when exercising *Not in accordance with health promotion* if older persons are afraid of getting injuries through exercises	*Negligence towards health* *In accordance with health promotion* if older persons may perform health-promoting activities according to their convenience *Not in accordance with health promotion* if older persons perceive preventive measures and treatment as inconvenient
Food consumption *In accordance with health promotion* if older persons prefer a healthy and balanced diet *Not in accordance with health promotion* if older persons have a preference for rich and tasty food	*Food abstinence* *In accordance with health promotion* if older persons want to make a diet to reduce body weight *No case of non-accordance reported*[a]
Sexual desire *Not relevant with regard to health promotion*	*Sexual abstinence* *Not relevant with regard to health promotion*
Social orientations of action	
Self-reliance *In accordance with health promotion* if older persons take responsibility for their health, search proactively for health-related information, and strive to maintain self-efficacy through exercising *Not in accordance with health promotion* if older persons are not inclined to become active regarding their health and do not take the initiative	*Being cared for* *In accordance with health promotion* if older persons feel safe due to careful coaching *Not in accordance with health promotion* if older persons like to get more attention and support than they receive in health-related programmes
Exerting influence on others *In accordance with health promotion* if older persons have choices, can express their opinion, make own decisions, are informed about the purpose of exercises *Not in accordance with health promotion* if older persons cannot exert influence on health-related programmes and feel exposed to pressure by instructors	*Attention to the needs of others* *In accordance with health promotion* if older persons do not have to bother others in order to promote their health *Not in accordance with health promotion* if older persons fear to become a burden with their attempts to promote their health

Table 4.7 (continued)

Social adjustment *In accordance with health promotion* if older persons feel comfortable when complying with advices from experts or significant others, develop a sense of obligations to a group, and gain an inner structure *Not in accordance with health promotion* if older persons lacked discipline or if they were left to do the exercises on their own	*Unconventionality* *In accordance with health promotion* if health-related activities do not disturb older persons' own way of life *Not in accordance with health promotion* if older persons dislike advices and feel constrained by rules and regulations
Closeness *In accordance with health promotion* if older persons gain social contacts in exercise groups *Not in accordance with health promotion* if group activities had a social climate that did not meet their social inclinations	*Distance* *In accordance with health promotion* if older persons who prefer social distance can exercise at home or in a fitness studio *Not in accordance with health promotion* if health promotion is a mass event and older persons dislike overcrowding
Identity-related orientations of action	
Work *In accordance with health promotion* if older persons have the feeling to perform meaningful activities that also contribute to physical fitness *Not in accordance with health promotion* if older persons perceive activities other than exercise as meaningful and therefore feel bored with exercises	*Relaxation* *In accordance with health promotion* if older persons can reduce mental stress and find relaxation through physical activities like walking *Not in accordance with health promotion* if health-related activities result in stress and prevent relaxation
Reflection *In accordance with health promotion* if older persons can meet their desire for cognitive integrity or satisfy intellectual interests through health-related activities *Not in accordance with health promotion* if older persons have other intellectual interests and therefore perceive exercises trivial	*Diversion* *In accordance with health promotion* if older persons have fun and entertainment during exercises *Not in accordance with health promotion* if older persons prefer other kinds of entertainment than exercising or derive pleasure from entertaining activities that may be harmful to health
Self-presentation *In accordance with health promotion* if older persons can leave a positive impression on others and feel valued and respected when participating in exercise groups *Not in accordance with health promotion* if health-related measures (e.g. using walker for fall prevention) or participation in activity groups prevented older persons from building their desired image	*Self-concealment* *In accordance with health promotion* if older persons remain unnoticed from others if they performed health-related activities *Not in accordance with health promotion* if older persons fear to attract the attention of others because of their physical limitations

(continued)

Table 4.7 (continued)

Self-centredness *In accordance with health promotion* if older persons feel that they can do something for themselves or if they are rewarded for efforts spent on exercising *Not in accordance with health promotion* if physical exercise becomes a duty that does not serve self-interest	*Concern for others* *In accordance with health promotion* if older persons can support others by advice and encouragement to promote their health *Not in accordance with health promotion* if health-related activities prevent older persons from showing concern for others who are of central importance for them (like children or grandchildren)
Positive self-perception *In accordance with health promotion* if older persons get a sense of achievement through exercising *Not in accordance with health promotion* if older persons cannot achieve a positive self-perception through participating in activity groups that feel inferior to other group members	*Critical self-perception* *In accordance with health promotion* if older persons get aware of their limitations and can adjust their physical activities accordingly *Not in accordance with health promotion* if older persons believe that they have no longer the abilities to participate in exercises because they have a negative self-image as a result of excessive self-criticism
Development-related orientations of action	
Attachment to the past *In accordance with health promotion* if older persons can continue their habitual physical activity *Not in accordance with health promotion* if older persons have no habit of exercising or if exercising gets into conflict with cultural norms	*Searching new perspectives* *In accordance with health promotion* if older persons are inclined to change, gain new knowledge, and are enabled to develop new habits and routines *No case of non-accordance reported*
Denial of adversities *In accordance with health promotion* if older persons can avoid unnecessary worries about health that may prevent them from participating in health-related activities *Not in accordance with health promotion* if older persons avoid to think about health risks	*Facing adversities* *In accordance with health promotion* if older persons have a proactive awareness of their vulnerability and contemplate a behaviour change *No case of non-accordance reported*
Hope *In accordance with health promotion* if older persons can combine hope or religious beliefs with health-related practices *Not in accordance with health promotion* if older persons get attached to unrealistic beliefs regarding maintaining their health	*Scepticism* *In accordance with health promotion* if older persons have realistic ideas and beliefs about health that prevent them from disillusionment and strengthen their composure *Not in accordance with health promotion* if older persons are too sceptical about health-related interventions and give up hope at all

[a] A case of non-accordance may occur in younger persons who suffer from anorexia. This condition is unlikely to be met among older persons

Encouragement to exercise may stimulate those who are inclined to physical rest, whereas those who tend to excessive exercising may need an advice to slow down.

In other cases, however, health-related interventions may have a negative impact on the satisfaction of older persons' orientation of action. For example, physical exercises that exceed the abilities of older persons provoke fear of injuries and contradict in this way their need for physical integrity. They may also interfere with the desires for self-presentation and a positive self-image if they prevent older persons from building a desired image and make them feel inferior to members of an activity group who still have more physical capacities.

The mismatch between quality of life according to older persons and health-related interventions as designed by experts is partly due to a different understanding of health. Whereas health experts focus narrowly on the maintenance of physical fitness and the prevention of diseases, older persons have a broader understanding of health. For them, health promotion is not a one-sided activity to promote physical fitness and strength in order to increase resistance to disease. Rather, it means finding an inner balance between physical effort and physical rest, between pleasure and restraint, and between attention to and negligence of health.

Furthermore, the aim of health promotion is not restricted to physical well-being. It is rather concerned about finding an inner balance at all four levels of the orientations of action. Health promotion programs with a narrow focus on fitness and functional improvement are likely to counteract social, identity-, and development-related needs. As an end in itself, the satisfaction of body-related orientations of action is rather meaningless. These orientations gain their final meaning by serving the satisfaction of the other orientations of action that are of greater importance in life. Due to this subordinated character of body-related orientations of action in the complete context of life older persons may perceive activities with no explicit focus on physical fitness as health promoting, whereas health experts may either ignore such activities or perceive them as a distracting from what they consider to be beneficial for health. For example, older persons may satisfy their need for entertainment and social contacts in a social environment that is not inclined to healthy behaviours. Although involvement in such a social environment may be rather detrimental to health from a medical point of view, older people will find it beneficial to their well-being as it allows them to avoid loneliness, which actually has a negative impact on health. In a similar way, concern for others may prevent participation in health promotion programs. However, helping others enables older people to find a purpose in life. For them, it has a higher priority and the health promoting value of their social engagement should be recognized.

Finally, one has to recall that health in old age does not simply mean to be physically fit and active as it is suggested by the idea of active and successful ageing. Sooner or later, older persons will suffer from functional limitations and they have to cope with their losses. In this context, health rather means to develop serenity in the face of physical limitations. Seen in this way, the limited interest in physical fitness as it was shown by some older persons is an attempt to restore an inner balance by finding a compensation for lost abilities at a higher level of the orientations of action. If older persons develop a positive acceptance of ageing, physical activities to prevent diseases and to increase fitness are no longer their priority. They may rather gain a sense of well-being that is based on inner peace and serenity and goes beyond the narrow perspective of active ageing that is inherent in most health promotion programs. This is not to say, that active ageing is a misleading attempt to promote health in old age. One should, however, be aware that a one-sided focus on fitness and activity is not suitable for everybody and needs to be counterbalanced with increasing age by an understanding of health that encompasses the satisfaction of identity- and development-related orientations of action.

If we keep this partial discrepancy between the promotion of physical fitness on the one hand and quality of life on the other hand in mind, we can close this chapter with the following recommendations for health promotion in a person-centred way:

- Public information on health-related issues should be clear and easy to understand in order to avoid confusion and uncertainty among recipients.
- Health promotion and disease prevention programs should be offered in the vicinity to avoid discouragement due to inconvenient transportation.
- Health promotion and disease prevention programs should be offered during the day as older persons feel insecure in the dark.
- Exercise groups should be composed of members with similar abilities to avoid feelings of inferiority and feelings of disturbing others with one’s limitations.
- Health advice and attempts to exert some influence may stimulate a behaviour change in older persons if they are made with caution.
- Instructors of exercise groups should avoid exerting pressure on participants, because older persons will feel overstrained and have the impression of being humiliated and losing control.
- Instructors should instead provide guidance to give participants a feeling of being cared for and at the same time they should offer choices and allow discussions to give participants a sense of control and a feeling of being respected.
- Instructors should give advices how to manage unpleasant symptoms when exercising in order to satisfy participant’s need for physical integrity.
- Group-based programs should offer the opportunity to socialize and get entertainment as the desires for closeness and amusement are main motives for participation.
- Health promotion programs should recruit participants by using the social network of older persons because encouragement by peers and significant others is an important trigger and satisfies the desire for being cared for.
- Older persons with a preference for social distance should be encouraged to exercise at home or in a fitness studio.
- Peer mentors may provide encouragement for those who prefer to exercise alone.
- Finally, health promoters should recognize that older persons may be less prone to physical activities due to an age-related decline of abilities or due to a lack of habit. Rather than insisting on a specific level of activity they should acknowl-

edge that performing everyday activities and participating in social events have a health promoting effect that meets the needs and abilities of older adults. Hence, supporting self-care activities and offering opportunities to socialize (not for the sake of exercising but for the sake of socializing) are essential components of health promotion.

References

Barenfeld E, Gustafsson S, Wallin L, Dahlin-Ivanoff S (2015) Understanding the “black box” of a health-promotion program: keys to enable health among older persons aging in the context of migration. Int J Qual Stud Health Well Being 10:29013

Barenfeld E, Gustafsson S, Wallin L, Dahlin-Ivanoff S (2017) Supporting decision-making by a health promotion programme: experiences of persons ageing in the context of migration. Int J Qual Stud Health Well Being 12:1337459

Belza B, Walwick J, Shiu-Thornton S, Schwartz S, Taylor MLJ (2004) Older adult perspectives on physical activity and exercise: voices from multiple cultures. Prev Chronic Dis 1(4):A09

Berlin Hallrup L, Albertsson D, Bengtsson Tops A, Dahlberg K, Grahn B (2009) Elderly women’s experiences of living with fall risk in a fragile body: a reflective lifeworld approach. Health Soc Care Community 17(4):379–387

Berry TR, Spence JC, Plotnikoff RC, Bauman A, McCargar L, Witcher C, Clark M, Stolp S (2009) A mixed methods evaluation of televised health promotion advertisements targeted at older adults. Eval Program Plann 32(2):278–288

Bethancourt HJ, Rosenberg DE, Beatty T, Arterburn DE (2014) Barriers to and facilitators of physical activity program use among older adults. Clin Med Res 12(1–2):10–20

Boggatz T (2011) Die Einstellung älterer Menschen zur Gesundheitsförderung – Eine qualitative Studie. Pflegewissenschaft 11(7–8):413–421

Boggatz T, Meinhart CM (2017) Health promotion among older adults in Austria: a qualitative study. J Clin Nurs 26(7–8):1106–1118

Brännström H, Bäckman M, Fischer RS (2013) Walking on the edge: meanings of living in an ageing body and using a walker in everyday life – a phenomenological hermeneutic study. Int J Older People Nursing 8(2):116–122

Bredland EL, Söderström S, Vik K (2018) Challenges and motivators to physical activity faced by retired men when ageing: a qualitative study. BMC Public Health 18(1):627–638

Cartwright T (2007) ‘Getting on with life’: the experiences of older people using complementary health care. Soc Sci Med 64(8):1692–1703

Chaudury M, Nicola Shelton N (2010) Physical activity among 60–69-year-olds in England: knowledge, perception, behaviour and risk factors. Ageing Soc 30:1343–1355

Collins CA, Decker SI, Esquibel KA (2004) Definitions of health. J Multicult Nurs Health 10(3):13–18

Costello E, Kafchinski M, Vrazel J, Sullivan P (2011) Motivators, barriers, and beliefs regarding physical activity in an older adult population. J Geriatr Phys Ther 34(3):138–147

DeLamater J (2012) Sexual expression in later life: a review and synthesis. J Sex Res 49(2–3):125–141

Dickinson A, Machen I, Horton K, Jain D, Maddex T, Cove J (2011) Fall prevention in the community: what older people say they need. Br J Community Nurs 16(4):174–180

Frenn M (1996) Older adults’ experience of health promotion: a theory for nursing practice. Public Health Nurs 13(1):65–71

Gilbert C, Hagerty D, Taggert HM (2012) Exploring factors related to healthy ageing. Self Care Depend Care Nurs 19(1):20–26

Graham LJ, Connelly DM (2013) “Any movement at all is exercise”: a focused ethnography of rural community-dwelling older adults’ perceptions and experiences of exercise as self-care. Physiother Can 65(4):333–341

Grasser C, Craft BJ (2000) The blessing of giving: the importance of reciprocity to self-health care. Geriatr Nurs 21(3):138–143

Gustafsson K, Sidenvall B (2002) Food-related health perceptions and food habits among older women. J Adv Nurs 39(2):164–173

Hardy S, Grogan S (2009) Preventing disability through exercise: investigating older adults’ influences and motivations to engage in physical activity. J Health Psychol 14(7):1036–1046

Horne M, Skelton D, Speed S, Todd C (2010) The influence of primary health care professionals in encouraging exercise and physical activity uptake among White and South Asian older adults: experiences of young older adults. Patient Educ Couns 78(1):97–103

Horne M, Skelton DA, Speed S, Todd C (2013) Perceived barriers to initiating and maintaining physical activity among South Asian and White British adults in their 60s living in the United Kingdom: a qualitative study. Ethn Health 18(6):626–645

Hung LW, Kempen GIJM, De Vries NK (2010) Cross-cultural comparison between academic and lay views of healthy ageing: a literature review. Ageing Soc 30:1373–1391

Hutton I, Frame R, Maggo H, Shirakawa H, Mulligan H, Waters D, Haie L (2000) The perceptions of physical activity in an elderly population at risk of falling: a focus group study. NZ J Physiother 37(2):85–92

Janssen SL, Stube JE (2014) Older adults’ perceptions of physical activity: a qualitative study. Occup Ther Int 21(2):53–62

Komatsu H, Yagasaki K, Saito Y, Oguma Y (2017) Regular group exercise contributes to balanced health in older adults in Japan: a qualitative study. BMC Geriatr 17(1):190

Leavy B, Aberg AC (2010) “Not ready to throw in the towel”: perceptions of physical activity held by older adults in Stockholm and Dublin. J Aging Phys Act 18(2):219–236

Lees FD, Clark PG, Nigg CR, Newman P (2005) Barriers to exercise behavior among older adults: a focus-group study. J Aging Phys Act 13(1):23–33

Lette M, Stoop A, Lemmens LC, Buist Y, Baan CA, de Bruin SR (2017) Improving early detection initiatives. A qualitative study exploring perspectives of older people and professionals. BMC Geriatr 17(1):132–145

Leung K-K, Wu E-C, Lue B-H, Tang L-Y (2004) The use of focus groups in evaluating quality of life components among elderly Chinese people. Qual Life Res 13(1):179–190

Li Y, Du X, Zhang C, Wang S (2013) Physical activity among the elderly in China: a qualitative study. Br J Community Nurs 18(7):340–348

Lorenc A, Clow A, Forte D, Robinson N (2012) “It keeps me going” – older people’s perception of well-being and use of complementary and alternative medicine (CAM). Qual Ageing Older Adults 13(2):135–144

MacDonald T (1998) Rethinking health promotion: a global approach. Routledge, London

Maddox M (1999) Older women and the meaning of health. J Gerontol Nurs 25(12):26–33

Mathews AE, Laditka SB, Laditka JN, Wilcox S, Corwin SJ, Liu R, Friedman DB, Hunter R, Tseng W, Logsdon RG (2010) Older adults’ perceived physical activity enablers and barriers: a multicultural perspective. J Aging Phys Act 18(2):119–140

McGrath M, Clancy K, Kenny A (2016) An exploration of strategies used by older people to obtain information about health- and social care services in the community. Health Expect 19(5):1150–1159

Menichetti J, Graffigna G (2016) How older citizens engage in their health promotion: a qualitative research-driven taxonomy of experiences and meanings. BMJ open 6(7):e010402

Miller KS (2010) Older adults’ perception of fall-prevention education: a qualitative study. Master thesis, Western Carolina University, Cullowhee

Miller AM, Iris M (2002) Health promotion attitudes and strategies in older adults. Health Educ Behav 29(2):249–267

Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med, 6 (7), e1000097

Morris Docker S (2006) Tai Chi and older people in the community: a preliminary study. Complement Ther Clin Pract 12(2):111–118

Nielsen G, Wikman JM, Jensen CJ, Schmidt JF, Gliemann L, Andersen TR (2014) Health promotion: the impact of beliefs of health benefits, social relations and enjoyment on exercise continuation. Scand J Med Sci Sports 24(Suppl. 1):66–75

Nusselder W J (2003) Compression of morbidity. In: Robine J M, Jagger C, Mathers C D, Crimmins E M, Suzman R M (Eds.). Determining health expectancies. Chichester: John Wiley & Sons Ltd., 35–38

Patzelt C, Heim S, Deitermann B, Theile G, Krauth C, Hummers-Pradier E, Walter U (2016) Reaching the Elderly: understanding of health and preventive experiences for a tailored approach: results of a qualitative study. BMC Geriatr 16(1):210–222

Price AE, Corwin SJ, Friedman DB, Laditka SB, Colabianchi N, Montgomery KM (2011) Older adults' perceptions of physical activity and cognitive health: implications for health communication. Health Educ Behav 38(1):15–24

Resnick B, Vogel A, Luisi D (2006) Motivating minority older adults to exercise. Cultur Divers Ethnic Minor Psychol 12(1):17–29

Seedhouse D (1997) Health promotion: philosophy, prejudice and practice. Wiley, Chichester

Shearer N, Fleury J (2006) Social support promoting health in older women. J Women Aging 18(4):3–17

Simmonds BAJ, Hannam KJ, Fox KR, Tobias JH (2016) An exploration of barriers and facilitators to older adults' participation in higher impact physical activity and bone health: a qualitative study. Osteoporos Int 27(3):979–987

Söderhamn O (1998) Self-care ability in a group of elderly Swedish people: a phenomenological study. J Adv Nurs 28(4):754–753

Söderhamn U, Dale B, Söderhamn O (2011) Narrated lived experiences of self-care and health among rural-living older persons with a strong sense of coherence. Psychol Res Behav Manag 4:151–158

Söderhamn U, Dale B, Söderhamn O (2013) The meaning of actualization of self-care resources among a group of older home-dwelling people: a hermeneutic study. Int J Qual Stud Health Well Being 19(8):1–9

Stevens Z, Barlow C, Iliffe S (2015) Promoting physical activity among older people in primary care using peer mentors. Prim Health Care Res Dev 16(2):201–206

Tengland PA (2010) Health promotion or disease prevention: a real difference for public health practice? Health Care Anal 18(3):203–221

van Leuven KA (2010) Health practices of older adults in good health. J Gerontol Nurs 36(6):38–46

Wang HH, Hsu MT, Wang RH (2001) Using a focus group study to explore perceptions of health-promoting self-care in community-dwelling older adults. J Nurs Res 9(4):95–104

WHO (1986) Ottawa charter for health promotion. WHO, Geneva

Quality of Life in Long-Term Care Facilities

5

5.1 Long-Term Care Facilities

For a variety of reasons older persons give up their old home and move into a long-term care facility. Ill-health, loss of self-care abilities, loss of a spouse or lack of support by the family, or a combination of these events are the main reasons for such a decision. Long-term care facility is a generic term that encompasses different kinds of institutions. Probably most familiar are nursing homes, but there are also assisted living facilities and alternative forms of nursing homes that need to be taken into consideration to get a better idea of the concept.

5.1.1 Nursing Homes

Nursing homes are a worldwide phenomenon. They originated in Western countries and spread on all continents. As a consequence, what is nowadays referred to as a nursing home may look quite different in every place of its existence. It would be beyond the scope of this book to provide a detailed description of the different kinds of institutions labelled as nursing homes that do exist worldwide. There are, however, three main characteristics that allow a broad distinction between them.

First of all, nursing homes are a housing option for older and sometimes also disabled people. Such housing options emerged in the Middle Ages from poorhouses that provided food and shelter for persons who were unable to care for themselves and had no source of income (Giarchi 2002). They were operated by the church or by charitable organizations and in some countries this charitable work became a matter of state regulations at the beginning of the seventeenth century—as, for example, in the UK with the provisions of the Elizabethan Poor Laws (Bright 2007).

In the twentieth century there was a growing awareness that residents of such housing facilities need more than just food and shelter. Residential facilities for older persons began to provide assistance in activities of daily living. At the same

T. Boggatz, *Quality of Life and Person-Centered Care for Older People*,
https://doi.org/10.1007/978-3-030-29990-3_5

time the demand for specialized medical and nursing services became apparent. In reaction to this development countries began enacting laws to ensure care for older persons. In the USA, for example, homes for the aged run by philanthropically funded organizations were turned into modern nursing facilities after the 1965 enactment of Medicare and Medicaid and they became hospital-like in their design and physical operation (Wilson 2007).

One may therefore define nursing homes provisionally as residential facilities that provide personal care and nursing care. Some countries, however, differentiate between such facilities by the level of care they aim to provide. In the UK, for example, there are care homes (personal) and care homes (nursing) (Bright 2007; Hillcoat-Nalletamby 2014; Stevens et al. 2015). Care homes (personal) primarily offer personal and social care. The staff is mainly composed of care assistants. Medical and nursing care is only available up to a certain level that can be met by external general practitioners or district nurses (Bright 2007). Residents who require a higher level of nursing care have to move to care homes (nursing) where registered nurses are on duty 24 h. A similar distinction exists in the Netherlands, where older people with less complex problems receive care in residential care homes, while disabled people with chronic physical diseases or with progressive dementia who need continuing care and monitoring are accommodated in nursing homes (Oosterveld-Vlug et al. 2014). According to this distinction, only facilities that meet the criteria of care homes (nursing) should be referred to as nursing homes.

In the international context, however, the term nursing home is not univocally used. In some countries as, for example, in Germany the difference between personal care homes and nursing care homes does not exist and facilities referred to as nursing homes include all types of residents that would be treated separately in the UK or the Netherlands. In other countries there are even facilities labelled as nursing homes that refuse to admit sick and care dependent older persons. Andrews (2012) describes nursing homes in India where residents are expected to be sufficiently mobile to get to the dining room for meals and were not allowed to suffer from age-related dementia to any significant extent. Shrestha and Zarit (2012) report about similar homes in Nepal, and in his own investigation in Egypt the author heard about facilities labelled as nursing homes that forced residents to move out when they became too dependent on help (Boggatz 2011). If one accepts that personal care and nursing care are essential features of nursing homes, such facilities should not be labelled as nursing homes.

The boundary between simple residences and nursing homes is, however, not always clear as there are also mixed cases. These so-called nursing homes are partly residential facilities as they host independent older persons and partly care homes for personal care that deny admission only to those who suffer from serious illness. Hweidi (1999) reports about such a home in Jordan, and the author learned in his own investigation from managers of care homes in Egypt (Boggatz 2011) that homes initially intended to serve as simple residential facilities began to include personal care as part of their service in reaction to the increasing care needs of their residents which emerged over time.

In his meanwhile classical ethnographic study Gubrium (1997) describes a nursing home as it existed in the 1970s in the USA. It also had a mixed composition of independent and care dependent residents, but both groups stayed in separate units. For the independent older persons the nursing home served mainly as a residential facility. Although such mixed facilities may still exist, there is an ongoing debate about whether to admit independent older persons to care homes which—as the argument goes—are basically designed to serve those who have extensive care needs. In consideration of the costs of care, there was a policy shift in many Western countries. Governments want to enable people to receive support in their own homes. Hence, independent older persons or persons with low-care needs who used to be placed in care facilities now remain at home and nursing homes tend to accommodate only people with high care needs (Twenhöfel 2007; Thomas et al. 2013). This shift was a reason why a distinction between care facilities according to levels of care became obsolete in some countries. Persons who need only some assistance in activities of daily living are on the way to disappear from nursing homes.

In summary, the term "nursing home" may refer to different kinds of facilities as shown in Fig. 5.1. In some counties there exists a distinction between simple residential facilities, care homes (personal), and care homes (nursing) and the term nursing home should only be applied to the latter. Other countries, however, do not differentiate between these two kinds of care homes and distinguish only between residential facilities and nursing homes in general. There are also countries where the term nursing homes may refer to facilities that are restricted to provide personal care. Such facilities may serve partially as simple residential facilities and it would be more appropriate to label them as homes for the aged. In some cases, finally, the term nursing home may be misleadingly applied to simple residential facilities.

There are several reasons why facilities labelled as nursing homes have such different admission policies. Economic resources, professional knowledge, ownership, and state regulations are the most obvious. A lack of economic resources as it exists in developing countries may simply prevent facilities to respond to needs for personal or nursing care. Teka and Adamek (2014) provide an example of such a care home in Ethiopia that was run by the regional government. It housed impoverished older adults who had no family support. There was an insufficient supply of food and care and a single nurse was available to treat the residents, who struggled to get even basic medicines such as eye drops and pain reliever. Forced to live at a subsistence level, some of the residents were observed begging outside. Similar care homes are often run by charitable organizations. Although sometimes criticized for their poor quality, they save their residents from living the life of the destitute and provide at least a shelter for those who have been abandoned (Rugh 1981; Andrews 2012; Shrestha and Zarit 2012).

<table>
<tr><td>Residential Facility</td><td>Care homes (personal care)</td><td>Care homes (nursing care)</td></tr>
<tr><td>Residential Facility</td><td colspan="2">Nursing homes</td></tr>
<tr><td colspan="2">Nursing homes/Home for the aged</td><td>-</td></tr>
</table>

Fig. 5.1 Different meanings of the term "nursing home"

A lack of economic resources is often associated with a lack of professional knowledge. Care homes in developing countries simply cannot afford to employ skilled nurses and are therefore afraid to accept physically and mentally ill individuals as they can only be treated by staff with no training in dealing with medical conditions (Shrestha and Zarit 2012). An own investigation gave the author some insight into the working conditions of such a home run by a convent of the Coptic church in Egypt (Boggatz 2011). The majority of the female caregivers was either illiterate or had just acquired basic skills in reading and writing. There was only one supervising nun who had absolved a three-month training course for care. Since they were unskilled workers, caregivers were not only in charge of personal care but also of all related household tasks including preparing meals, cleaning the home, and washing the residents' clothes. Paradoxically, this nursing home accepted older persons who had been rejected by the nearby governmental home due to their needs for personal care. Care was based on the ideal of charity and caregivers were expected to treat residents as if they were members of their own family.

Facilities in developed countries have better economic resources that allow the employment of nursing assistants and fully trained nurses who serve as supervisors. Their degree of service and comfort, however, may be quite different. High-end facilities may provide private rooms and other amenities like recreation rooms, a café (Andrew and Wilson 2014), a library (Fraher and Coffey 2011), or a garden (Raske 2010) for their residents, whereas low-cost facilities may be deprived of such amenities and residents are forced to stay in shared rooms. There are also nursing homes that offer different degrees of service and comfort and residents may choose to stay in a single room or a shared room according to their financial resources.

Such differences may be due to the ownership of the facilities. Ownership falls into either the public or the independent sector. In the public sector homes are run by governmental or local authorities, in the independent sector they are owned by charitable organizations or private organizations from large for-profit companies down to small, one-person businesses (Bright 2007; Giarchi 2002). Private for-profit organizations are likely to address older persons with high-end demands, whereas charitable organizations will take care of the more needy population. But there are also combinations of different kinds of ownership. Charitable homes, for example, may receive public funds (Giarchi 2002) or supplement their operating costs by also offering better service against private payments so that they work partly for profit (Boggatz 2011; Shrestha and Zarit 2012). Which kind of ownership is dominant depends on the orientation of the welfare system which varies between countries. In the UK, for example, the bulk of older people's long-term care provision moved into the independent sector due to changes in the funding policy (Bright 2007; Bowers et al. 2009). In other countries like Norway nursing homes are owned and run by the municipality, financed by taxes and resident payment (Nakrem et al. 2013).

State regulations are a further reason for differences between nursing homes. Many countries enacted laws that determine minimum standards of care and there are also independent commissions that carry out inspections to ensure quality of care. There is a variety of such rules and regulations that vary from country to country. Developing countries, however, may lack appropriate rules and regulations. In many Latin American countries, for example, there are no laws that regulate or facilitate financial oversight of care providing institutions (Figueredo-Borda and Zabalegui-Yárnoz 2015). Furthermore, the existence of laws does not guarantee their implementation. The registry of care facilities may be incomplete due to ineffective bureaucracy or because providers try to circumvent regulations that rather serve the purpose of bribery than the purpose of quality assurance (as the author had to learn during his work and investigation in Egypt). Due to a lack of "formal" inspection bodies and operational standards to monitor and evaluate care, care homes in Middle Eastern countries like Lebanon, Jordan, or Egypt are allowed "free reign" to set their own admission criteria, standards of care, and working practices (Hweidi 1999; Boggatz 2011; Adra et al. 2015).

5.1.2 Assisted Living

A description of long-term care facilities would be incomplete without taking into account alternatives to nursing homes that have emerged in some countries since the 1980s. Probably the best-known alternative is assisted living. It evolved as a response to a growing criticism of nursing homes that had a focus on medical care and were designed like hospitals. They were accused of subjecting residents to rigid control and depriving them of autonomy, privacy, and their individual way of life. Wilson (2007) who was among the pioneers of assisted living described the discontent of her mother with the nursing home and her vision of an alternative:

> Her vision was simple. She wanted a small place with a little kitchen and a bathroom. It would have her favourite things in it […] There would be people to help her with the things she couldn't do without help. In this imaginary place, she would be able to lock her door, control her heat, and have her own furniture. No one would make her get up, turn off her favourite soaps, or ruin her clothes. […] She could have privacy whenever she wanted, and no one could make her get dressed, take her medicine, or go to activities she did not like. She would be Jessie again, a person living in an apartment instead of a patient in a bed. (Wilson 2007)

Facilities that aimed to put this vision into practice mushroomed in the 1990s and at the beginning of this millennium there were about 11,500 assisted living facilities with more than half a million residents all over the USA (Hawes et al. 2003). Due to the rapid spread of assisted living, various types of facilities emerged that operated under this label. What was initially a specific model of care became a more generic term that referred broadly to housing and supportive services in a homelike environment (Zimmerman and Sloane 2007). In an attempt to clarify the concept, a national workgroup convened by the U.S. Senate Special Committee on Aging defined assisted living as residences that "provide or coordinate oversight and services to meet individualized scheduled needs, based on assessments and service plans, and unscheduled needs". Services were expected to include 24-h awake staff, provision and oversight of personal and supportive services, health-related services (excluding nursing care), social services, recreational activities, meals, housekeeping, laundry, and transportation (Assisted Living Workgroup 2003). Unfortunately, this definition was only accepted in parts by the majority of the workgroup attendees and due to this lack of a national consensus, states created their own definitions of assisted living (Zimmerman and Sloane 2007).

As a consequence, facilities that operate under the label of assisted living may look quite different. Some of them resemble rather nursing homes; others are similar to hotels and focus on concierge-type services such as housekeeping, laundry, meals, activities, and transportation, but view personal care and health-related services with reluctance. A third type is characterized by residential-style settings, a variable service capacity, a philosophy of consumer autonomy, and comes closest to the original idea of assisted living (Wilson 2007). All facilities, however, have in common that the main part of care and work is performed by aides who often just received on-the-job training (Ball et al. 2009). A qualified nurse may be employed in addition full- or part-time. This is the case in the majority of facilities but it is not obligatory (Hawes et al. 2003).

Due to the rapid growth of assisted living in the USA other countries took up the idea. Similar facilities, for example, were established in the UK where they were labelled as extra care housing. These were purpose-built housing schemes providing residents with a private flat, access to a range of nonmedical, low-level care, and support services, with communal facilities such as a dining area, organized social activities, and a 24-h support staff presence (Hillcoat-Nalletamby 2014).

Assisted living and extra care housing should not be confused with facilities that are known in the USA as independent living or congregate housing and in the UK as sheltered housing. The latter can be characterized as a simple “housing with support” that provides only limited service by a regular on-site “warden” or scheme manager, but no 24-h care on a regular base (Pannell and Blood 2012). In contrast, assisted living facilities are similar to care homes that provide personal care. In theory, the difference between these two kinds of facilities is that assisted living is oriented to support autonomy and privacy in a homelike environment. In practice, however, it may be difficult to distinguish both as there are also nursing homes that offer private rooms and are designed in a homelike style, whereas some assisted living facilities may look like nursing homes and accommodate residents in shared rooms.

It should be added that there are also combinations of nursing homes, assisted living, and independent living facilities. These so-called continuing care retirement communities are composed of separate sections each for a particular level of care dependency. They aim to allow for ageing in place so that residents may enter the independent living section and move with increasing care needs to the assisted living section until they reach the nursing home as their final destination.

5.1.3 Alternatives to Nursing Homes

The criticism of nursing homes did not only result in the emergence of assisted living that operated outside the framework for nursing homes (although in some states such facilities were eligible to receive funds from Medicaid). There were also attempts to change the nursing home culture from within. The best-known example is the Eden Alternative™ that was developed by Dr. Thomas, an American geriatrician who redesigned a nursing home in Upstate New York to make it a more human habitat. Integral to the Eden design was the introduction of plants, animals, and children into the nursing home to counteract boredom and loneliness among residents and to promote a "life worth living". Medical treatment became secondary to caring. The locus of decision-making was with the residents, and by interaction with plants, animals, and children they should have the opportunity to give care as well as to receive it (Hinman and Heyl 2009; Brownie and Horstmanshof 2012).

A recent development that grew out of Eden principles at the beginning of this millennium are The Green House homes™. These are small-house nursing homes that try to combat the negative effects of institutionalization by changing the architectonical and organizational structure of nursing homes (Zimmerman and Cohen 2010). Most Green House homes are built in clusters of two or three, and each accommodates 6–12 residents. Residents have private rooms and bathrooms that open onto a central living area. The physical environment resembles a family home (Zimmerman and Cohen 2010; Bowers and Nolet 2014).

Staff empowerment is a further cornerstone of this idea. The hierarchy is flattened. Caregivers at the level of certified nursing assistants work in self-managed teams and are responsible for direct resident care, cleaning, laundry, meal preparation, and social activities. They simulate the way how families might organize work (Rabig et al. 2006; Zimmerman and Cohen 2010; Bowers and Nolet 2014), and they are called "Shahbazim" (singular: "Shahbaz")—an expression derived from Persian language which literally means royal falcon and refers to a fabled bird in Iranian mythology. A nurse is available 24 h a day and the clinical care team is nearby and visits as needed, but according to the philosophy of "demedicalizing" the atmosphere they are rather in the background (Bowers and Nolet 2014).

Such small house homes had predecessors in other countries. The idea of group-living care emerged already at the beginning of the 1980s in Sweden with the foundation of a model project in Malmö (Annerstedt 1997). At the end of the same decade the Anton-Piekhofje in the Netherlands was established to accommodate small groups of people with dementia who live in private rooms and share a common recreational and dining room (Kennemerhart 2018). Since the 1990s similar group-living units evolved in Germany. All these units have in common that they protect privacy and promote at the same time social interaction because residents spent the majority of the daytime together in a central lounge and kitchen area (Simon et al. 2013).

Green houses and other small house homes are similar to assisted living with regard to the limited presence of qualified nurses. They aim to provide an environment where residents can feel at home and maintain their daily life. These are central goals of person-centred care. Ironically, they are pursued by facilities where few nurses are employed and these facilities were established because nursing homes were accused of being unable to provide such person-centred care. One is tempted to ask whether the nursing profession failed to achieve a goal which is central to the idea of holistic nursing. On the other hand, one may also ask whether assisted living and other alternatives to nursing homes are able to achieve these goals—given the lower qualification of staff and the ensuing lack of specialization. It should be noted that the idea to simulate family life in a care environment was similar to the ideal of care in Egyptian nursing homes that were described above. The underlying assumption seems to be that care does not require special expertise and that it occurs rather naturally when staff cooks and cleans for residents.

5.1.4 Long-Term Care and Quality of Life

Given this background the question arises: what are the experiences that residents make in these different kinds of long-term care facilities? How do nursing homes and their alternatives impact on older persons' quality of life? Composition and qualification of staff in long-term care facilities may be quite different, but from the perspective of residents all types of facilities have one thing in common: Persons who move in have to give up their old home. As a consequence, they have to deal with this change and their new environment will have a positive or negative influence on their quality of life.

This chapter will describe how such environments support or interfere with the older persons orientations of action. It is based on an extensive literature research in the databases Pubmed, CINAHL, and Embase as shown in Fig. 5.2. The research

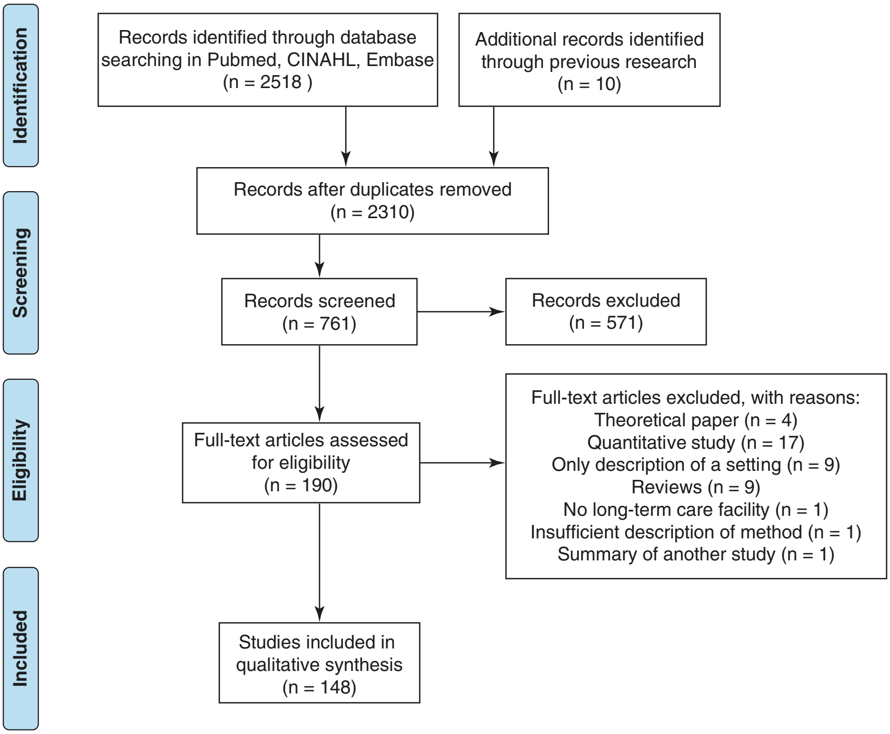

Fig. 5.2 Search strategy according to PRISMA (Moher et al. 2009)

was restricted to studies published in either English or German that were not older than 20 years. There was no restriction regarding place or kind of long-term care setting except for studies that described simple residential facilities with no staff available to provide personal care. Studies were included if they had a qualitative design and investigated the perceptions of residents in long-term care facilities by interviewing and/or observation. Since qualitative studies depend on the information provided by the participants, the perspective of older people with dementia could not be obtained unless they were included in observational studies. Studies that compared residents of long-term care facilities with home-dwelling older adults were included if the experiences of both groups were described separately. Because caregivers are in close contact to care recipients and exert a strong influence on their perceptions qualitative studies that investigated their point of view were also included. In several cases studies tried to capture both perspectives simultaneously. Research questions were allowed to have a broad focus on residents' experience in general or a narrow focus on a particular aspect of their experience like social contacts, independence, sexuality, etc. which was useful to shed some light on those aspects that may remain unnoticed if the study is concerned about experiences in general.

Altogether, 148 studies were included. Table 5.1 provides an overview over the places and settings, and Table 5.2 details their research questions, participants, and methods. 101 studies were conducted in facilities labelled as nursing homes, the others

Table 5.1 Studies by country and setting

	Nursing home	Assisted living	Total
USA	13	34	47
Canada	10	1	11
Australia	8	1	9
New Zealand	2	–	2
Norway	10	–	10
Sweden	10	4	14
Finland	2	–	2
Island	1	–	1
UK	11	2	13
Ireland	7	–	7
Germany	6	–	6
The Netherlands	3	–	3
Switzerland	1	–	1
Spain	4	–	4
Taiwan	5	–	4
China	2	–	2
South Korea	2	–	2
Indonesia	2	–	2
Middle East	4	–	4
Others	4	–	4
Total	106	42	148

Table 5.2 Investigated studies by authors and date of publication

Author(s)	Country	Facility	Research question	Participants	*n*	Data collection by	Research tradition
Adra et al. (2015)	Lebanon	NH	To explore the perspectives of quality of life for a sample of older residents, care staff, and family caregivers	Residents (65–91 years)	20	Interviews	Not specified
				Family members	8		
				Staff	11		
Al-Omari et al. (2005)	USA	AL	To describe the culture of an assisted living facility	Residents (77–83 years)	4	Interviews and participant observation	Ethnography
Andersson et al. (2007)	Sweden	NH	To describe older people's experiences of daily life at the care home after admittance	Residents (69–90 years)	13	Interviews	Not specified
				Family members	10		
				Staff	11		
Andrew and Wilson (2014)	New Zealand	NH	To explore the value of a café on the premises of an aged care facility for residents and their families	Residents (no age range specified)	11	Interviews	Interpretive description
				Family members	9		
Andrews (2012)	India and Australia	RCF	To identify characteristics of Anglo-Indian institutions and their residents' attitudes towards living in them	Residents (no age range specified)	40	Interviews and participant observation	Ethnography
Ball et al. (2000)	USA	AL	What represents quality in the lives of residents in assisted living	Residents (>65 years)	55	Interviews and participant observation	Grounded theory
Ball et al. (2004a)	USA	AL	To investigate the process of ageing in place in assisted living	Residents (no age range specified)	39	Interviews and participant observation	Grounded theory
				Family members	28		
				Staff	39		

Ball et al. (2004b)	USA	AL	To understand the meaning of independence for residents of assisted living	Residents (no age range specified)	55	Interviews and participant observation	Grounded theory
Ball et al. (2009)	USA	AL	How direct care workers in assisted living facilities interpret their relationships with residents	Staff (direct care workers)	38	Interviews and participant observation	Grounded theory
Barnes et al. (2013)	UK	NH	To describe individual residents' mealtime experience	Residents (no age range specified)	n. s.	Structured and unstructured observation	Not specified
Bauer et al. (2013)	Australia	NH	Residents' perceptions of needs and barriers to expression of sexuality in long-term care	Residents (79–101 years)	16	Interviews	Constructivism
Behr et al. (2013)	Germany	NH	How do residents experience situations that touch there intimate sphere	Residents (no age range specified)	42	Interviews	Not specified
Behr et al. (2014)	Germany	NH	To analyse mental fitness and mobility according to nursing home residents	Residents (no age range specified)	44	Interviews	Not specified
Bergland and Kirkevold (2006)	Norway	NH	Residents' perspective on what contributes to thriving in a nursing home	Residents (74–103 years)	26	Interviews	Phenomenology
Bennett et al. (2015)	USA	AL	To explore resident autonomy in assisted living and the effects visitors have on it	Residents (no age range specified)	68	Interviews and participant observation	Ethnography
				Family members	47		
				Staff	65		
Bland (2007)	New Zealand	NH	To explore the nature of comfort within the context of nursing homes	Residents (66–91 years)	21	Interviews and participant observation	Critical ethnography

(continued)

Table 5.2 (continued)

Author(s)	Country	Facility	Research question	Participants	*n*	Data collection by	Research tradition
Boggatz et al. (2009)	Egypt	NH	To identify the attitudes of Egyptian nursing home residents towards staying in a nursing home	Residents (Ø 72 years)	21	Interviews	Hermeneutics
Bollig et al. (2016)	Norway	NH	What nursing home residents and their relatives perceive as ethical challenges in nursing homes	Residents (66–100 years)	25	Interviews	Not specified
				Family members	18	Focus groups	
Bourrett et al. (2002)	Canada	NH	The meaning of mobility for residents and staff	Residents (>60 years)	20	Focus groups	Not specified
				Staff	15		
Bowers et al. (2001)	USA	NH	How nursing home residents define quality of care	Residents (64–104 years)	27	Interviews	Grounded theory
Bowers et al. (2009)	UK	NH AL	To learn from the experiences and aspirations of older people who currently live in care homes	Residents (no age range specified)	84	Participant observation and group discussion	Not specified
Canham et al. (2016)	Canada	NH	To explore meanings and experiences of “home” from the perspective of paid staff members	Staff	32	Interviews	Not specified
Carder (2002)	USA	AL	How daily operations in assisted living are affected by its central values	Residents (no age range specified) and staff	n.s.	Participant observation	Ethnography
Chang (2013)	South Korea	NH	To understand the experiences of life among nursing home residents	Residents (76–96 years)	11	Interviews	Descriptive phenomenology
Cheng et al. (2011)	China	RCF	To understand the well-being of residents and how the environment affects everyday activities and health	Residents (Ø 80 years)	27	Interviews	Not specified
				Family members	26		
				Staff	18		

Chin and Quine (2012)	Australia	RCF	Concern about residential aged care by older women in low-care facility	Residents (>65 years)	25	Interviews	Not specified
Cho et al. (2017)	South Korea	NH	To explore older adults' perceptions of their daily lives in South Korean nursing homes	Residents (65–94 years)	21	Interviews	Not specified
Christov (2016)	Germany	NH	To understand community and silence in a nursing home	Residents (no age range specified)	12	Interviews and participant observation	Ethnography
Chuang and Abbey (2009)	Taiwan	NH	To explore and understand the culture of nursing home life for older residents in Taiwan	Residents (no age range specified)	16	Interviews and participant observation	Ethnography
				Family members	17		
				Staff	4		
Chuang et al. (2015)	Taiwan	NH	To explore the older nursing home residents' care needs from their own perspectives.	Residents (Ø 81 years)	18	Interviews	Not specified
Cooney et al. (2009)	Ireland	NH	To identify the determinants of quality of life for older people living in residential care	Residents (>65 years)	101	Interviews	Grounded theory
Cooney (2011)	Ireland	NH	To understand older peoples' perceptions of "being at home" in long-term care settings	Residents (>65 years)	61	Interviews	Grounded theory
Coughlan and Ward (2007)	Canada	NH	Residents' experiences in a LTCF and their understanding of "quality of care"	Residents (Ø 84 years)	18	Interviews and participant observation	Not specified
Curle and Keller (2010)	Canada	NH	To investigate social interactions at mealtime in retirement homes	Residents (no age range specified)	n. s.	Participant observation	Ethnography

(continued)

Table 5.2 (continued)

Author(s)	Country	Facility	Research question	Participants	*n*	Data collection by	Research tradition
Dobbs (2004)	USA	AL	To explore the meanings of "home" and "care" for residents in assisted living	Residents (no age range specified)	n. s.	Participant observation and informal interviews	Ethnography
Dobbs et al. (2008)	USA	AL	To explored aspects of stigmatization for older adults in residential care or assisted living	Residents (no age range specified)	153	Interviews and participant observation	Ethnography
				Family members	76		
				Staff	80		
Donaldson et al. (2014)	USA	AL	To explore attitudes of heterosexual residents towards gay and lesbian peers	Residents (62–90 years)	13	Interviews	Interpretive phenomenology
Donnelly and MacEntee (2016)	Canada	NH	How do residents perceive care in LTC facilities purporting to offer person-centred care?	Residents (58–97 years)	23	Interviews	Grounded theory
Eckert et al. (2009)	USA	AL	To explore transitions in the life of residents in assisted living	Residents (no age range specified)	150	Interviews and participant observation	Ethnography
Eika et al. (2015)	Norway	NH	To explore nursing staff interactions during the older residents' transition into long-term care facilities	Residents (no age range specified)	10	Interviews and participant observation	Ethnography
				Staff	17		
Falk et al. (2013)	Sweden	NH	To understand processes and strategies by which older people create a sense of home in residential care	Residents (Ø 82 years)	25	Interviews	Grounded theory
Figueredo-Borda and Zabalegui-Yárnoz (2015)	Uruguay	RCF	To explore the perception of care in long-term centres	Residents (74–99 years)	7	Interviews and participant observation	Ethnography
				Staff	15		

Fiveash (1998)	Australia	NH	Resident's experience of nursing home living	Residents (>65 years)	8	Interviews (2 or 3 times) and participant observation	Ethnography
Fraher and Coffey (2011)	Ireland	NH	To explore older people's decision to relocate to long-term care and their early experiences post-relocation	Residents (78–92 years)	8	Interviews	Interpretive phenomenology
Frankowski and Clark (2009)	USA	AL	How sexuality permeated the lives of assisted living residents, staff, and family members	Residents (no age range specified)[a]	150	Interviews and participant observation	Ethnography
Goddard et al. (2013)	UK	NH	To explore the views and experiences of care home resident's family on dignity therapy	Family members	14	Interviews	Not specified
Grando et al. (2000)	USA	NH	Reasons why elders with light-care needs reside in nursing homes	Residents (55–98 years)	98	Interviews	Not specified
Grant et al. (1996)	Canada	NH	Indicators of quality of care	Residents (25–99 years)	52	Interviews	Critical incidence technique
				Family members	58		
				Staff	37		
Grau et al. (1995)	USA	NH	To assess residents' best and worst experiences in the nursing home	Residents (Ø79 years)	46	Interviews	Grounded theory
Gustavsson et al. (2015)	Sweden	NH	To examine how residents and staff at a nursing home described the residents' everyday doings	Residents (69–97 years)	15	Interviews	Not specified
				Staff	6		

(continued)

Table 5.2 (continued)

Author(s)	Country	Facility	Research question	Participants	*n*	Data collection by	Research tradition
Hauge and Heggen (2006)	Norway	NH	How and to what extent the idea of the nursing home as a home has been realized	Residents (80–100 years)	24	Interviews and participant observation	Interpretive phenomenology
Harmer and Orrell (2008)	UK	NH	To explore concepts of meaningful activity, as defined by residents with dementia staff and family carers	Residents (72–99 years)	17	Focus groups	Grounded theory
				Family members	8		
				Staff	15		
Heid et al. (2016)	USA	NH	Preferences of residents and why they change	Residents (Ø79 years)	39	Rating scale and open questions	Cognitive interviewing
Heliker (2009)	USA	NH	To investigate the experience of participating in a story sharing intervention	Residents (>60 years)	54	Interviews	Interpretive phenomenology
				Staff	84	Focus group discussion	
Heliker and Scholler-Jaquish (2006)	USA	NH	To describe the experience of being admitted to and living in a nursing home	Residents (no age range specified)	10	Interviews (3 times)	Interpretive phenomenology
Hellström and Sarvimäki (2007a, b)	Sweden	AL	How residents in sheltered housing experience self-determination and how they are valued as human beings	Residents (73–93 years)	11	Interviews	Not specified
Herrmann and Flick (2011)	Germany	NH	To explore the nursing home residents' self-perceived resources for good sleep	Residents (66–101 years)	30	Interviews	Not specified
Hillcoat-Nalletamby (2014)	UK	NH AL[b]	To understand the meaning of independence for older persons in extra care housing and nursing homes	Residents (NH) (Ø 82 years)	29	Interviews	Not specified
				Residents (AL) (Ø 81,5 years)	29		

Hjaltadóttir and Gustafsdóttir (2007)	Island	NH	To disclose the characteristics of quality of life as perceived by frail but lucid residents in nursing homes	Residents (76–93 years)	8	Interviews	Interpretive phenomenology
Holmberg et al. (2013)	USA	NH	How the work environment supported or impeded caregiving to residents	Staff	150	Focus groups	Not specified
Holmgren et al. (2013)	Sweden	NH	To describe how nursing staff's routines and reasoning condition the involvement of relatives in nursing homes	Staff	42	Interviews and participant observation	Ethnography
				Residents (no age range specified)	n. s.	Participant observation	
				Family members	n. s.		
Hubbard et al. (2003)	UK	NH	To understand social interaction in institutional care settings	Residents (no age range specified)	n. s.	Participant observation	Ethnography
Hutchinson et al. (2011)	USA	NH	To investigate person and environmental factors that facilitate adaptation to nursing facilities	Residents (>60 years)	23	Interviews	Phenomenology
Hwang et al. (2013)	Taiwan	NH AL	To elucidate the nature of caring by describing the experience of elderly residents of Taiwan LTCFs	Residents (65–94 years)	12	Interviews	Not specified
Hweidi (1999)	Jordan	NH	To describe the culture of a nursing home in Amman, Jordan	Residents (no age range specified)	17	Interviews and participant observation	Ethnography

(continued)

Table 5.2 (continued)

Author(s)	Country	Facility	Research question	Participants	*n*	Data collection by	Research tradition
Iden et al. (2015)	Norway	NH	To explore residents' perceptions of their own sadness	Residents (>80 years)	12	Interviews and participant observation	Not specified
Iwasiw et al. (1996)	Canada	NH	Residents' perspectives of the first two weeks in LTC	Residents (no age range specified)	12	Interviews	Grounded theory
Iwasiw et al. (2003)	Canada	NH	To explore residents' perspectives of their first year in a nursing home	Residents (75–88 years)	7	Interviews (5 times)	Phenomenology
				Family members	3		
James et al. (2014)	Sweden	NH	To describe how residents develop a meaningful daily life	Residents (83–100 years)	25	Interviews (2 times)	Action research and hermeneutic
Jordan (2010)	USA	AL	How residents in ALF perceive nurses' caring behaviour	Residents (67–99 years)	51	Questionnaire and interviews	Mixed method
Karlsson et al. (2009)	Sweden	NH	To describe registered nurses' experiences of their work environment in residential care homes	Staff	12	Interviews	Not specified
Kemp (2008)	USA	AL	How married couples experience life in assisted living	Residents (66–94 years)	20	Interviews	Grounded theory
Kemp et al. (2012)	USA	AL	Social relationships in assisted living and their influencing factors	Residents (52–102 years)	27	Interviews and participant observation	Not specified
				Staff	16		
Kemp et al. (2016)	USA	AL	Relationships of married and unmarried couples in assisted living	Residents (59–100 years)	51	Interviews and participant observation	Grounded theory
Kennedy et al. (2005)	USA	AL	The experience of older adults in making everyday decisions in assisted living	Residents (63–76)	4	Interviews and participant observation	Case study

Koch-Straube (2003)[c]	Germany	NH	To describe everyday life in a nursing home	Residents (74–95 years)	41	Participant observation and informal interviews	Ethnography
				Staff	24		
Koppitz et al. (2017)	Switzerland	NH	To understand unplanned admissions to nursing homes and to explore its impact on adaptation	Residents	31	Interviews	Not specified
Koskenniemi et al. (2015)	Finland	NH	To describe how older patients in nursing homes and their kin experience the manifestation of respect	Residents (69–90 years)	40	Interviews	Not specified
				Family members	20		
Kuhn (2008)	USA	AL	To explore how the social world in assisted living is organized	Residents (no age range specified)	22	Interviews and participant observation	Ethnography
				Staff	17		
Lung and Liu (2016)	China (Hong Kong)	NH	To identify the types of daily interactions perceived by NAs and residents	Residents (71–96 years)	15	Interviews	Not specified
				Staff	18		
Mahrs Träff et al. (2017)	Sweden	AL	To explore how residents and staff understand the concept of physical activity	Residents (70–95 years)	13	Interviews	Phenomenography
				Staff	17		
Martinsson et al. (2013)	Sweden	NH	To illuminate older immigrants' experiences of moving to a residential care facility	Residents (67–87 years)	7	Interviews	Not specified
Melin-Johansson et al. (2014)	Sweden	NH	To explore experiences of ageing among residents based on the gerotranscendence theory	Residents (80–96 years)	14	Interviews	Not specified

(continued)

Table 5.2 (continued)

Author(s)	Country	Facility	Research question	Participants	*n*	Data collection by	Research tradition
Minney and Ranzijn (2016)	Australia	AL	Residents' perspectives on whether a "good life" is possible for older people living in residential aged care	Residents (77–95 years)	13	Interviews	Interpretive phenomenology
Mohammadinia (2017)	Iran	NH	To explore the older peoples' experiences of nursing homes	Residents (65–82 years)	15	Interviews	Descriptive phenomenology
Murphy (2007)	Ireland	NH	To explore nurses' perceptions of quality care in long-term care	Staff	20	Interviews	Interpretive phenomenology
Murphy et al. (2007)	Ireland	NH	To explore the quality of life in long-stay care from the perspectives of residents and staff	Residents (>65 years)	101	Interviews, focus groups, and survey	Mixed method
				Staff	48		
Nakrem et al. (2011)	Norway	NH	To describe nursing homes' residents experience with direct care	Residents (75–96 years)	15	Interviews	Not specified
Nakrem et al. (2013)	Norway	NH	To describe residents' experiences of living in a nursing home related to quality of care	Residents (75–96 years)	15	Interviews	Not specified
Nakrem (2015)	Norway	NH	To describe the nursing home culture from the staff's perspective and how the residents describe quality of care	Residents (75–92 years)	15	Interviews	Ethnography
				Staff	n. s.	Participant observation and informal interviews	
Nay (1992)	Australia	NH	The meaning of sexuality for older women in nursing homes	Residents (>50 years)	20	Interviews	Not specified

Naess et al. (2016)	Norway	NH	How different care practices affect nursing home residents' dignity and sense of self	Residents (no age range specified)	n. s.	Participant observation	Ethnography
				Staff	48	Interviews and participant observation	
Nord (2013)	Sweden	AL	Meaning of household possessions that residents brought with them when moving into assisted living	Residents (60–99 years)	11	Interviews	Not specified
Oakes and Sheehan (2012)	USA	AL	How employees in assisted living give meaning to the term autonomy	Staff (direct care workers)	18	Interviews	Not specified
Oosterveld-Vlug et al. (2013a)	The Netherlands	NH	To investigate if and how nursing home residents' personal dignity changes over the course of time	Residents (49–97 years)	22	Interviews (2 to 5 times)	Not specified
Oosterveld-Vlug et al. (2013b)	The Netherlands	NH	To gain insight how nurses and physicians view dignity of nursing home residents	Staff	28	Interviews	Not specified
Oosterveld-Vlug et al. (2014)	The Netherlands	NH	To gain insight how residents experience personal dignity and the factors that preserve or undermine it	Residents (49–102 years)	30	Interviews	Not specified
O'Shea et al. (2014)	Ireland	NH	To explore relatives' involvement in the care of older adults admitted to residential settings	Family members	9	Interviews	Not specified
Palacios-Ceña et al. (2013)	Spain	NH	To explore the significance of the mealtime experience among residents of nursing homes in Spain	Residents (62–95 years)	26	Interviews	Descriptive phenomenology

(continued)

Table 5.2 (continued)

Author(s)	Country	Facility	Research question	Participants	*n*	Data collection by	Research tradition
Palacios-Ceña et al. (2016a)	Spain	NH	To describe how Spanish nursing home residents experienced and made sense of meaningful activities	Residents (62–100 years)	38	Interviews	Descriptive phenomenology
Palacios-Ceña et al. (2016b)	Spain	NH	To describe the lived experience of sexuality in elderly Spanish women residing in nursing homes	Residents, only women (Ø 83 years)	20	Interviews	Descriptive phenomenology
Park et al. (2009)	USA	AL	How male residents interact with other residents and staff in assisted living	Residents (>65 years)	29	Questionnaire and interviews	Mixed method
Park et al. (2012)	USA	AL	To explore the experience of social engagement in assisted living	Residents (Ø 85 years)	29	Interviews	Not specified
Park et al. (2013)	USA	AL	To explore social relationships of African American and Hispanic assisted living residents	Residents (>60 years)	30	Interviews	Not specified
Perkins et al. (2012)	USA	AL	To develop a conceptual model of autonomy in assisted living	Residents (>65 years)	266	3 previous studies with interviews	Metasynthesis
Perkins et al. (2013)	USA	AL	To examine the relative importance of co-resident relationships and other network ties	Residents (42–102 years)	179	Questionnaire and open ended questions	Mixed method
Philpin et al. (2011)	UK	NH	To investigate factors that influenced nutritional care provided in residential care settings	Residents (>65 years)	16	Interviews, focus groups, and participant observation	Not specified
				Staff	19		
Pryce and Gooberman-Hill (2012)	UK	NH	To explore the factors affecting communicating with a hearing loss in residential care	Residents (76–99 years)	18	Interviews and participant observation	Ethnography

Raske (2010)	USA	NH	To evaluate the impact of an enabling garden on quality of life of nursing home residents	Residents (65–99 years)	16	Interviews	Not specified
				Family members	6		
				Staff	15		
Rahayu et al. (2018)		NH	To understand the experience of older persons living in a residential home	Residents	6	Interviews	Phenomenology
Rekawati et al. (2018)		NH	To determine the effect of a partnership model to increase quality of life of older people in nursing home	Residents	8	Interviews	Phenomenology
Roberts and Bowers (2015)	USA	NH	To explore the ways resident develops relationships with peers and staff in nursing homes	Residents (55–97 years)	15	Interviews and participant observation	Grounded theory
Robichaud et al. (2006)	Canada	NH	Quality of life indicators in LTC for residents and family members	Residents (Ø 82 years)	19	Interviews	Not specified
				Family members	8		
Rossen and Knafl (2003)	USA	AL	To explore the transition of elder women to assisted living	Residents (61–91 years)	31	Interviews (pre- and post-move)	Not specified
Sandhu et al. (2013)	USA	AL	To examine the influences of physical and mental function on co-resident relationships in assisted living	Residents (54–102 years)	24	Interviews and participant observation	Grounded theory
				Staff	16		
Saunders and Heliker (2008)	USA	AL	The experience of older women after admission to assisted living	Residents (63–91 years)	5	Interviews (7 times)	Not specified
Schenk et al. (2013)	Germany	NH	To identify dimensions of life that residents perceive as having particular impact on their overall quality of life	Residents (no age range specified)	43	Interviews	Not specified

(continued)

Table 5.2 (continued)

Author(s)	Country	Facility	Research question	Participants	*n*	Data collection by	Research tradition
Shaw et al. (2016)	UK	AL	To understand older adults' experiences of moving into extra care housing	Residents (66–85 years)	6	Interviews (3 times)	Interpretive phenomenology
Shin (2008)	USA	NH[b]	To explore older Korean Americans' preferences when they are bedridden	Residents (nursing homes) (63–92 years)	5	Interviews	Not specified
Shin (2015)	USA	CCRC	How residents interact with their physical and social environments	Residents (no age range specified)	17	Interviews and participant observation	Grounded Theory
Shippee (2009)	USA	CCRC	How residents define transitions between levels of care in a CCRC	Residents (76–99 years)	35	Interviews and participant observation	Not specified
Shrestha and Zarit (2012)	Nepal	RCF[b]	How older women define and assess their quality of life	Residents (73–91 years)	5	Interviews	Not specified
Sidenvall et al. (1994)	Sweden	NH	How residents experience the meal situation and the intentions of staff regarding this situation	Residents (Ø 81 years)	18	Interviews and participant observation	Ethnography
				Staff	18		
Slettebo et al. (2016)	Norway/ Sweden/ Denmark	NH	How nursing home residents experience dignity through the provision of activities that foster meaning and joy	Residents (62–103 years)	28	Interviews	Not specified
Speller and Tollee (2015)	Canada	AL	To determine the gaps and strengths in care related to safety in assisted living	Residents (no age range specified)	9	Interviews	Not specified
				Staff	13		
Stathi and Simey (2007)	UK	NH	To explore exercise experiences of residents who participated in an exercise intervention	Residents (86–99 years)	14	Interviews (before and after intervention)	Interpretive phenomenology

Stevens et al. (2015)	UK	NH	To explore the experiences of older people with minimal care needs admission to care homes with RN care	Residents (86–99 years)	12	Interviews	Grounded theory
Svidén et al. (2009)	Sweden	AL	How older persons experience moving to and living at sheltered housing.	Residents (no age range specified)	59	Interviews	Not specified
Taylor et al. (2014)	Australia	NH	To explore residents’ perspectives of intrinsic factors influencing mobility and their associations	Residents (61–96 years)	15	Interviews	Ethnography
Teka and Adamek (2014)	Ethiopia	RCF	To explore psychosocial needs in a residential care centre from the perspective of both staff and residents	Residents (>60 years)	24	Focus groups	Not specified
				Staff	5	Interviews	
Thomas et al. (2013)	Australia	RCF	To investigate residents’ perceptions and experiences of social interaction and leisure activity	Residents (Ø 84 years)	6	Interviews	Not specified
Timonen and O’Dwyer (2009)	Ireland	NH	Experiences and coping strategies of (older) people living in residential care	Residents (no age range specified)	12	Interviews and group meetings	Not specified
Tompkins et al. (2012)	USA	AL	To understand the perceived continuity of relationships with family and friends	Residents (>65 years)	29	Interviews	Not specified
Tsai and Tsai (2008)	Taiwan	NH	To the lived experiences of older nursing home residents in Taiwan	Residents (65–97 years)	33	Focus groups and interviews	Not specified

(continued)

Table 5.2 (continued)

Author(s)	Country	Facility	Research question	Participants	*n*	Data collection by	Research tradition
Tucket (2007)	Australia	NH	Residents and staff's perception of the nursing home	Residents (70–88 years)	19	Interviews, group discussion, participant observation	Grounded theory
				Staff	38		
Tuominen et al. (2016)	Finland	NH	To describe older people's experiences of free will, its actualization, promoters, and barriers in nursing homes	Residents (68–96 years)	15	Interviews	Descriptive phenomenology
Villar et al. (2014)	Spain	NH	To compare views of staff and residents about barriers to sexual expression in residential aged care facilities	Residents (71–96 years)	47	Interviews	Not specified
				Staff	53		
Walker and Curry (2007)	USA	NH	How do older adults experience moving from their primary residence to a long-term care facility	Residents (no age range specified)	8	Interviews	Not specified
		AL			8		
Walker and Paliadelis (2016)	Australia	NH	To investigate the lived experience of older people in residential aged care	Residents (77–96 years)	18	Interviews	Interpretive phenomenology
Warren and Williams (2008)	USA	AL	The experience of assisted living and common problems for residents	Residents (no age range specified)	21	Interviews	Grounded theory
Westin and Danielson (2007)	Sweden	NH	To illuminate the meaning of residents' experiences of encounters with nurses in nursing homes	Residents (78–99 years)	12	Interviews	Hermeneutic
Williams and Warren (2008)	USA	AL	Experiences of older women in assisted living	Residents (no age range specified)	21	Interviews and participant observation	Grounded theory

Williams and Warren (2009)	USA	AL	How staff communicates with residents in assisted living	Residents	8	Interviews	Not specified
				Staff	8	Focus group	
Wilson and Davies (2009)	UK	NH	How relationships between residents and staff develop	Residents (no age range specified)	16	Interviews, focus groups, and participant observation	Constructivism
				Family members	18		
				Staff	25		
Wright et al. (2010)	UK	AL	To explore tenants' experiences of living in a remodelled extra care scheme and staff views about working there	Residents	96	Interviews	Not specified
				Staff	56		
Wu et al. (2009)	Taiwan	NH	To understand the phenomenon of nursing home care for older people in Taiwan	Residents	40	Interviews	Grounded theory
				Family members	20		
Wu and Barker (2008)	USA	NH	To explore the mealtime experience of Chinese elders in American nursing homes	Residents (Ø 81 years)	7	Interviews and participant observation	Grounded theory
				Family members	9		
				Staff	19		
Zimmerman et al. (2016)	USA	CCRC	How structures and processes of care in CCRC result in stigma in assisted living and nursing homes	Residents (39–100 years)	113	Interviews	Ethnography
				Family members	40		
				Staff	101		

n.s. not specified

NH nursing home, *AL* assisted living (including Extra Care Homes), *RCF* residential care facility, *CCRC* continuing care retirement community

[a] Same participants as Eckert et al. (2009)

[b] Study included participants from other settings, but data from these settings were excluded from evaluation

[c] Revised edition of a study originally published 1997

in assisted living facilities. Regarding the location, 61 came from European countries (mainly Norway, Sweden, and the UK), 57 from North America (mainly the USA), 11 from Australia and New Zealand, 11 from the Far East (China, Taiwan, South Korea, and Indonesia), four from the Middle East (Egypt, Jordan, Lebanon, and Iran), and four from others countries (i.e. Ethiopia, India, Nepal, and Uruguay). The findings were analysed and synthesized by using the same method as described in Chap. 2.

5.2 Long-Term Care Facilities and Body-Related Orientations of Action

Moving into a long-term care facility is often a reaction to meet body-related needs. Due to functional limitations older persons may have difficulties to move around, to satisfy their need for food and drink, to take care of their hygiene, to use the toilet, or to protect their body against injuries. The facility is expected to safeguard their physical integrity. At the same time it will interfere with the way how older persons are used to care for these needs. Behaviour of staff, but also rules and regulations may either promote or impede the satisfaction of body-related orientations of action. Table 5.3 provides an overview over the different aspects of body-related orientations of action and their satisfaction, the factors that influence this satisfaction and the behavioural and attitudinal reactions that residents use to deal with their situation.

5.2.1 Physical Activity Versus Physical Rest

5.2.1.1 Physical Activity

Despite their functional limitations older persons in long-term care facilities expressed a *desire for physical activities*. Residents in assisted living facilities said that they wanted to exercise according to their abilities (Ball et al. 2004b; Minney and Ranzijn 2016; Mahrs Träff et al. 2017)

> I think you've got to be occupied—physically and mentally occupied—I would say. There's nothing worse than being idle. We've got the gymnasium, which I attend fairly regularly. (Minney and Ranzijn 2016)

But also those who stayed in nursing homes considered physical activity to be beneficial for their health and they tried at least to walk around in the home (Tsai and Tsai 2008; Hutchinson et al. 2011; Nakrem et al. 2011; Chuang et al. 2015; Slettebo et al. 2016)

> I stayed in bed one day, and I thought it was just terrible. Even if I'm not feeling 100% I get up, because I improve as the day goes on. (Bourrett et al. 2002)

The main motivation for their efforts to stay physically active was the *desire for mobility*, i.e. the ability to move around according to their own desire (Stathi and Simey 2007; Cooney et al. 2009; Nakrem et al. 2013; Schenk et al. 2013; Behr et al. 2014; Taylor et al. 2014)

Table 5.3 Body-related orientations of action, influencing factors, behavioural and attitudinal reactions

Orientations of action and their satisfaction	
Physical activity	Desire for physical activity
	Desire for mobility
Satisfaction of physical activity	Intrinsic pleasure
	Benefits for health
	Improved mobility
	Restricted opportunities for physical activity
	Decline of mobility and energy
Physical rest	Desire to rest and recover
	Need for improved sleep
Satisfaction of physical rest	Having a rest and nap
	Sleep disorders
	Overexertion
Body protection and regeneration	Avoidance of injuries
	Concern about hygiene
	Fear of deteriorating health
	Getting treatment and therapy
	Hoping to recover by staying at home
	Desire for pain relief
	Importance of physical comfort
	Desire for wellness
	Rejecting treatment or care believed to be risky
Satisfaction of body protection and regeneration	Improved health and well-being
	Experiencing a sense of wellness
	Decline of health
	Falls
	Pain
Negligence towards health	Ignoring minor ailments
	Limited desire for hygiene
Satisfaction of negligence towards health	Leaving minor ailments untreated
	Minimum of hygiene
	Inconvenience
Food consumption	Desire to eat well
Satisfaction of food consumption	Enjoyment of meals
	Gain in weight
	Less satisfied with food
	Bad quality of food
	Remaining hungry
Food abstinence	Avoidance of overeating
	Keeping a diet
	Loss of appetite
Satisfaction of food abstinence	Normal blood sugar
	Surfeit
Sexual desire	Desire for sexual contact
	Desire for intimacy

(continued)

Table 5.3 (continued)

Satisfaction of sexual desire	Sexual pleasure
	Sexual frustration
Sexual abstinence	Dislike of sexual duties
	Remaining abstinent as a widow
	Abandoned sexual desires
Satisfaction of sexual abstinence	Sexual harassment
	Marital rape
Influencing factors	
Physical conditions	Ill-health
	Functional limitations
	Sexual disability
Environmental factors	Accessibility for disabled persons
	Availability of assistive devices
	Security systems
	Inconvenient beds
	Noise
	Inappropriate room temperature
	Problems getting medication
	Distribution of clothes for the needy
	Quality and quantity of meals
	Unavailability of double beds for couples
	Private room for occasional use
Body-related care	Room cleaning
	Personal care
	Assistance for eating and toileting
	Treatment of wounds
	Monitoring of vital parameters
	Medication
	Health promotion
	Lack of hygiene
	Neglect of mobilization and sleep promotion
Behavioural and attitudinal reactions	Exercises
	Walking
	Using assistive devices
	Taking prescribed medication
	Taking a nap
	Acceptance of physical limitations
	Slowing down

> I'd like to be able to go out, to be more independent, to be able to go to the toilet myself. I'd like to be able eventually to go out to the shop – that's the one thing you miss terribly. (Cooney et al. 2009)

Some residents told how they struggled to regain or maintain mobility

> I've started walking down, almost down, to the kitchen every mealtime. I nearly get there I try and do as much as I can. It's will power really to get me to do it (Taylor et al. 2014)

5.2.1.2 Satisfaction of Physical Activity

Satisfaction of the desire for physical activity was associated with *intrinsic pleasure* (Bourrett et al. 2002; Slettebo et al. 2016; Mahrs Träff et al. 2017). As one resident of an assisted living facility put it:

> It's moving physically and feeling good (Mahrs Träff et al. 2017)

Other residents told about *benefits for their health* (Ball et al. 2004a; Herrmann and Flick 2011; Minney and Ranzijn 2016; Cho et al. 2017). Physical activity promoted sleep and helped to reduce functional limitations.

> One becomes tired because one walks a lot, is outside in the fresh air. (Herrmann and Flick 2011)

> I walk everyday. My old legs, they give me trouble on account of these veins, and that helps (Ball et al. 2004a)

As a consequence of exercising, residents experienced an *improved mobility* (Stathi and Simey 2007; Oosterveld-Vlug et al. 2013a; Mahrs Träff et al. 2017). Even if such improvement was small, it was still perceived to be a success:

> That I am able to move, even if it's slow going (Mahrs Träff et al. 2017)

There were, however, other residents who could not satisfy their desire to stay active. Some of them complained about *restricted opportunities for physical activities* (Tsai and Tsai 2008; Behr et al. 2014; Bollig et al. 2016; Heid et al. 2016)

> There are seldom any activities. I don't have anything to do. […] All I do here is eat. They don't even provide any space for us to take a walk. (Tsai and Tsai 2008)

Others reported about a *decline of mobility and energy* which was partly due to their health condition, but also partly due to such restricted opportunities (Cooney et al. 2009; Cheng et al. 2011; Falk et al. 2013; Thomas et al. 2013; Shaw et al. 2016; Cho et al. 2017)

> If I got better, I could be more hopeful, but I feel weaker day by day. The distance that took 5 minutes for me to walk [before] now takes 10 minutes, which makes me frustrated. (Cho et al. 2017)

> At first when I moved in, I could manage on my own and now I'm unable to even stand straight without my walker. (Falk et al. 2013)

5.2.1.3 Physical Rest

On the other hand, residents in long-term care facilities also expressed a *desire to rest and recover*. For some of them the favourite time was "lunch and nap" (Ball et al. 2000). They were content with their physical capacities and did not feel like improving them (Minney and Ranzijn 2016). This attitude was in particular explicit among residents who suffered from ill-health and frailty (Nakrem et al. 2013; Heid et al. 2016)

> When I was healthy I went. Now that I'm not healthy, I can't. I have to go with the flow so to speak. (Heid et al. 2016)

Furthermore, some residents complained about sleep disturbances and felt a *need for improved sleep* at night (Herrmann and Flick 2011; Schenk et al. 2013; Chuang et al. 2015).

5.2.1.4 Satisfaction of Physical Rest

The desire for physical rest was satisfied when residents were able *to have a rest and nap* (Thomas et al. 2013). Others, however, were not able to overcome their *sleep disorders* (Iwasiw et al. 1996; Timonen and O'Dwyer 2009; Herrmann and Flick 2011; Chang 2013; Chuang et al. 2015). As one of them told:

> I don't sleep, I just stare at the wall. (Iwasiw et al. 1996)

Such sleep disorders had a variety of reasons: a noisy environment in shared rooms, a lack of physical activity during the day, depression, or an inability to achieve inner calmness. Another disturbance of physical rest was an *overexertion* that occurred when residents had to engage in exhausting activities or therapies (Thomas et al. 2013; Gustavsson et al. 2015; Donnelly and MacEntee 2016). In reaction they refused to participate:

> I get dizzy and my legs start shaking and I don't want to fall down and break something. So I've had an argument with our physiotherapist [who said] 'you should walk, you should walk more'. Well … they're my legs and I know if I can stand up or not, and I told her 'get off my back', so she left me alone. (Donnelly and MacEntee 2016)

5.2.2 Body Protection and Regeneration Versus Negligence Towards Health

5.2.2.1 Body Protection and Regeneration

Physical activity could not only result in overexertion, it implied also risks for physical integrity that residents in long-term care facilities wanted to protect. They were concerned about the *avoidance of injuries* when they exercised or walked around (Fiveash 1998; Grando et al. 2000; Ball et al. 2004b; Stathi and Simey 2007; Falk et al. 2013; Speller and Tollee 2015). For this reason they appreciated a health protective environment with sufficient lighting and grab bars in the bathroom and around the home.

> To me [safety] means that everything is in its place and there is nothing around you can trip over… carpets are taped down where I walk, and everything is in its place. (Speller and Tollee 2015)

Some of them used assistive devices like walkers or canes, others asked for the assistance of caregivers to move around.

> I like it more for protection. If I'm a little bit wobbly, I feel more secure if I have something to push me along. (Ball et al. 2004b)

To protect their physical integrity some residents were also *concerned about hygiene* in order to prevent infections.

> The toilet is very clean, which is good for health. (Chuang et al. 2015)

Behind these particular concerns was the general fear of a deterioration in health, which, as one could observe when looking at other residents, seemed to be everyone's fate.

> I'm sick and there's sick people everywhere (Fiveash 1998)

When residents were ill they wanted *to get treatment and therapy* (Hjaltadóttir and Gustafsdóttir 2007; Hwang et al. 2013). Older persons who had been admitted to a nursing home because of ill-health sometimes *hoped to recover by staying in the home* (Bland 2007; Tsai and Tsai 2008; Chuang and Abbey 2009). They considered the long-term care facility to be a place of treatment and not a place of living.

> I came here after my stroke. My sons have to work and have no time to take care of me, so they sent me here. This place is like a hospital, with nurses and doctors. I can have better care than if I stay home…. The important thing to me now is to improve my health. (Tsai and Tsai 2008)

Residents who were ill had above all a *desire for pain relief* (Nakrem et al. 2011; Schenk et al. 2013; Chuang et al. 2015). Those who suffered from impairments told about the *importance of physical comfort* that could be achieved with the help of caregivers by small changes of their body position (Bowers et al. 2001; Cooney et al. 2009; Iden et al. 2015).

> It is of great importance for me that I am in a good sitting position […] if I am not sitting well, I feel sad. (Iden et al. 2015)

Some residents were not only concerned about the relief of physical discomfort, they also had a *desire for wellness* and asked for care that actively promoted comfort, such as being offered a refreshing shower on a hot summer's day (Bland 2007) or getting food similar to or higher than the body temperature because—as residents in Taiwanese nursing homes told—it was better for health (Chuang et al. 2015). Sometimes, however, residents *rejected treatment or care they believed to be risky* for their health (Nakrem et al. 2011). One resident, for example, who had injured her knee was offered knee prosthesis, but she did not dare to be operated. Another resident refused to be showered because he became exhausted and dizzy:

> I can't shower anymore. Just have to wash myself here (in the room). I did it (shower) at first but just had to give up. I would just fall, you know. It was my decision; I just said I couldn't do it. (Nakrem et al. 2011)

5.2.2.2 Satisfaction of Body Protection and Regeneration

Some older persons could satisfy their need for physical regeneration. They told about their *improved health and well-being* since their admission to the facility because the new environment was clean and healthy or because they received an appropriate therapy (Cheng et al. 2011; Minney and Ranzijn 2016).

> I'm able to concentrate on the physical side with the help of the gymnasium program, the masseur which I have once a month - I have a full body massage. I've got physiotherapists who look after my back and leg problems. (Minney and Ranzijn 2016)

Others told about moments when they *experienced a sense of wellness*, for example, when they felt like a new-born person after getting a bath (Koch-Straube 2003).

On the other hand there were residents who felt that their health was somewhat under threat due to a lack of hygiene:

> I often watch [the nurses] when they are doing the medication. They can be awful running their hand through their hair. And another thing very few of them have in their possession handkerchiefs. They just use the back of their hand but I am sorry to have to bring this up but it is true and another thing yeah they don't bring handkerchiefs for their nose or anything, it is not good enough. (Timonen and O'Dwyer 2009)

More serious, however, was the *decline of health* experienced by many residents (Hutchinson et al. 2011; Shrestha and Zarit 2012; Heid et al. 2016)

> How old age becomes difficult that as the body is attacked by diseases, the body becomes weak and frail, and life becomes troublesome. (Shrestha and Zarit 2012)

Their health condition sometimes worsened due to *falls* (Chang 2013; Shaw et al. 2016) which could be triggered by inappropriate furniture.

> If I want to get out of the bed, my legs must go down completely first. The other day, after I happened to miss this side rail, I fell down. (Chang 2013)

For these reasons it is not surprising that residents complained about *pain* that apparently could not be alleviated in several cases (Bergland and Kirkevold 2006; Timonen and O'Dwyer 2009; James et al. 2014; Mohammadinia et al. 2017)

> When you are in pain there is nothing done about it… I am sometimes in a lot of pain—for months in pain. (Timonen and O'Dwyer 2009)

> But there is evil everywhere in the body, the skeleton, and the belly. I have huge problems… It is quite unnecessary to have to live like this. (James et al. 2014)

5.2.2.3 Negligence Towards Health

Not every resident, however, was seriously concerned about the protection and regeneration of his body. Some of them tended to *ignore minor ailments* and did not seek medical treatment in these cases.

> Well if I had a headache it's unimportant or if I had a cold it's unimportant. […] It depends on the severity of the condition. (Heid et al. 2016)

Some male residents also had a *limited desire for hygiene* and were reluctant to take a bath—partly because they did not like it, partly because it had become inconvenient due to functional limitations (Koch-Straube 2003; Martinsson et al. 2013; Heid et al. 2016).

> Nobody understands me! I do not want to take a shower so often. (Martinsson et al. 2013)

> At the present time I do not take a tub bath or shower bath because I cannot stand up. So my choices are really confined to what I can do at the present time. I guess it was [more important] when I was at home and was able to take a shower every day. But since it's not possible, it's not as important right now. (Heid et al. 2016)

5.2.2.4 Satisfaction of Negligence Towards Health

As the quotations above suggest, negligence towards health was met when residents could *leave minor ailments untreated* and felt comfortable with a *minimum of hygiene*. More care for their health seemed to involve *inconvenience* for them and they only showed signs of worry when they were suffering from serious health problems.

5.2.3 Food Consumption Versus Food Abstinence

5.2.3.1 Food Consumption

Physical activity and rest were not only related to residents' attitudes regarding body protection, they also interacted with their balance between food consumption and abstinence. Meals were an important event in the daily life and residents had a *desire to eat well* (Tsai and Tsai 2008; Hutchinson et al. 2011; Palacios-Ceña et al. 2013; Chuang et al. 2015: Iden et al. 2015).

> I have nothing to do here [nursing home] but eat. Therefore it [eating] is very important in my daily life. (Tsai and Tsai 2008)

Some residents appreciated good meals because they had gone through hardships like war or economic crises in their life.

> I have experienced much hunger… Being able to eat four times a day is a privilege… (Palacios-Ceña et al. 2013)

For others food was an integral part of their family tradition and remembered them to the good old times when they had joy and pleasure in their life.

> Well, the culture of New Orleans is known for their red beans and rice, they gumbo, they jambalaya. I keep all that in my head that I can remember. (Hutchinson et al. 2011)

5.2.3.2 Satisfaction of Food Consumption

The desire for good food was met to varying degrees. Several residents told how they *enjoyed the meals* provided by the facility (Raske 2010; Wright et al. 2010; Cheng et al. 2011; Palacios-Ceña et al. 2013; Andrew and Wilson 2014; Figueredo-Borda and Zabalegui-Yárnoz 2015; Koppitz et al. 2017; Rekawati et al. 2018)

> They cook a different, tasty meal here every day, they […] feed us well. (Figueredo-Borda and Zabalegui-Yárnoz 2015)

> They provide the meals and we get to choose what we want… I would give the meals four stars. (Koppitz et al. 2017)

Enjoyment of meals depended to some extent on the expectation of residents. If expectations were low, they were easily satisfied. Facilities for better-off had to offer more to satisfy their residents.

> Well we had fresh salmon, was it Thursday, one day last week? It was beautiful. And we had turkey at the weekend. What more can we want? (Wright et al. 2010)

Some residents who enjoyed their meals reported about a *gain in weight* (Cheng et al. 2011; Chang 2013).

> [Before coming to the nursing home,] I was so skinny and weighed only 33 kg. I ate nothing at the hospital and stayed at home for 10 days, but now I eat well without overeating. That's how I get better. I gain weight and get better… (Chang 2013)

Others, however, were *less satisfied with the food*. Some were disappointed because meals were ready-made and not homelike (Nakrem et al. 2013); others said that they were not healthy because they lacked fresh fruits and vegetables (Bollig et al. 2016). Whereas these residents found meals at least acceptable, others openly complained about *bad quality of food* as it was not according to their taste or did not meet their cultural habits and some did not eat the food offered to them (Wu and Barker 2008; Timonen and O'Dwyer 2009; Cheng et al. 2011; Chuang et al. 2015).

> …the food is still just the same, sometimes you can't even eat the meat. Especially the so-called lamb, I think he died before he was killed! (Timonen and O'Dwyer 2009)

> The rice is cold. The vegetables are cold… This is not good for the elderly to eat. (Chuang et al. 2015)

Sometimes, complaints did not concern the quality but the quantity of food and residents reported that they *remained hungry* (Sidenvall et al. 1994; Tsai and Tsai 2008; Teka and Adamek 2014). This was an issue for facilities in developing countries where scarcity of resources prevented the provision of adequate meals. One resident in an Ethiopian nursing home, for example, complained:

> I eat to survive. But, I don't think we are receiving a balanced diet that is needed for older adults. (Teka and Adamek 2014)

Surprisingly, however, similar complaints were sometimes also raised in industrialized countries:

> There are smaller portions here than at home, where you get your plate filled. And at home you can take a little more… As a rule, I eat everything I get here, and it's not much. I am not fed very well. (Sidenvall et al. 1994)

Koch-Straube (2003) argues that meals in nursing homes are one of the rare sources of pleasure and entertainment for residents, but quite often they do not satisfy these needs. Hence, residents feel hungry despite a sufficient quantity of food.

5.2.3.3 Food Abstinence

The desire for a good meal was counterbalanced by a tendency *to avoid overeating* (Sidenvall et al. 1994; Cohen-Mansfield et al. 1995; Tuominen et al. 2016). Some residents felt uncomfortable when they were offered a standard portion and requested to get half of it. Others left what they could not eat on the plate. They had adapted their food intake to their lower consumption of energy which was consequence of their restricted opportunities for physical activity. Others wanted to restrict the intake of calories and *to keep a diet* because they suffered from diabetes (Cho et al. 2017). There were, however, also residents who were no longer interested in eating at all. If they ate, it was for them just an intake of calories, but nothing that was associated with pleasure. This *loss of appetite* was not only a reaction to food that did not satisfy their needs but also a sign that they did not enjoy their life (Koch-Straube 2003).

5.2.3.4 Satisfaction of Food Abstinence

Residents who kept their diet were satisfied when they succeeded in maintaining a *normal blood sugar*.

> Since I came here, I've been living in a regular pattern and eating whatever is given to me; so, my diabetes has been better, and I've been healthier. If I were home, I would have eaten whatever I wanted. (Cho et al. 2017)

If residents, however, ate more than they could they suffered from *surfeit* (Sidenvall et al. 1994; Cohen-Mansfield et al. 1995). This happened because they felt obliged to empty their plate since they had grown up during war times and had been taught that it was a sin to waste food.

5.2.4 Sexual Desire Versus Sexual Abstinence

5.2.4.1 Sexual Desire

Body-related orientations of actions also concerned sexuality. As we saw in Chap. 2, older persons do not like to talk about this issue because it does not conform to cultural norms they had learned when they had grown up. This does, however, not mean they do not have such desires. In contrast to home-dwelling older persons, residents in long-term care facilities have limited opportunities to hide such desires due to restrictions of their privacy. Staff sometimes could not avoid witnessing sexual activities of residents. Intimate relationships of varying degrees and manifestations occurred among couples, but there were also instances of solo masturbation (Frankowski and Clark 2009). Sexual relationships were not restricted to assisted living facilities that allow for more privacy, they were also observed in nursing homes (Naess et al. 2016). Some residents of long-term care facilities openly described a *desire for sexual contact* (Nay 1992; Frankowski and Clark 2009; Bauer et al. 2013)

> You don't lose your feelings as you age. I don't feel old. You never lose the need for love and intimacy. Sex is funny. It isn't just for younger people; it's for old people too. Just because you've suddenly got old, you've still got the same feelings. (Nay 1992)

> I always look under the bed for a man. (Bauer et al. 2013)

Sexual desire did not necessarily imply intercourse. Several residents expressed a *desire for intimacy* that just consisted of physical touch (Frankowski and Clark 2009; Bauer et al. 2013; Palacios-Ceña et al. 2016b)

> To snuggle up together is lovely you know… you don't have to have intercourse but you can have a cuddle. I miss that. (Bauer et al. 2013)

5.2.4.2 Satisfaction of Sexual Desire

To some extent residents were able to satisfy their sexual desire and they had *sexual pleasure*—either as couples or alone by masturbation (Nay 1992; Frankowski and Clark 2009). For others, however, sexual desires remained unsatisfied and they experienced *sexual frustration* (Nay 1992; Bauer et al. 2013; Villar et al. 2014). One reason was the lack of privacy that prevented them from fulfilling their desire.

> I used to masturbate once a month, but the worse off (more dependent) I got … (the less I masturbated). I don't feel private. (Bauer et al. 2013)

Another reason was a lack of appropriate partners as it was told by an older woman:

> It's complicated, firstly because here most people are women and… you know, there are few men and most of them are too old! (Villar et al. 2014)

As a consequence they missed the pleasures they had when they were younger.

5.2.4.3 Sexual Abstinence

Not all residents, however, shared such sexual desires. Some women spoke about their *dislike of sexual duties* they had to perform for their husband when they had been married.

> Many times I didn't want to do it, but I repeated to myself that it was my duty and his right… (Palacios-Ceña et al. 2016b)

For other older women, who had a more pleasurable sex-life, sexuality was only allowed in a marriage, and hence they wanted *to remain abstinent as a widow*.

> Having sexual relations with another person, even remarrying, feels as if I am betraying my beliefs, my Church, the vow I made when I got married (Palacios-Ceña et al. 2016b)

Finally, there were those residents who had *abandoned sexual desires*, because they perceived themselves to be too old (Frankowski and Clark 2009; Bauer et al. 2013)

> It's finished [sex and intimacy], you don't think about it, or you try not to think about it. (Bauer et al. 2013)

5.2.4.4 Satisfaction of Sexual Abstinence

Given the fact that many residents were not inclined to be sexually active, older persons in long-term care facilities had no problem to satisfy their desire for sexual abstinence. There were, however, instances that female residents felt *sexually harassed* by male residents who made attempts to satisfy their sexual desire.

> When a man gets right into bed, sits down, and goes under the covers, it's sexual harassment and it has gone too far. (Frankowski and Clark 2009)

In the described incidence the female resident finally had to call the police because caregivers and the administrator of the assisted living facility had ignored her complaints about the male resident. In another case, a caregiver assumed that *marital rape* was occurring in the relationship of a couple under her care (Frankowski and Clark 2009).

5.2.5 Influencing Factors

The satisfaction of body-related orientations of action depended on the residents' physical condition, environmental factors, and the care they received from staff members. In response, residents tried of course to cope with their situation.

5.2.5.1 Physical Condition

Physical activities of residents in long-term care facilities were restricted by *ill-health* and ensuing *functional limitations* which were often a reason for their admission to the long-term care facility (Sidenvall et al. 1994; Hweidi 1999; Andersson et al. 2007; Tsai and Tsai 2008; Chuang and Abbey 2009; Curle and Keller 2010; Chang 2013; Thomas et al. 2013; Hillcoat-Nalletamby 2014; Oosterveld-Vlug et al. 2014; Heid et al. 2016; Rekawati et al. 2018). Mobility impairments increased the risk of falling and prevented residents from walking and exercising. In serious cases, residents lost the ability to clean and dress themselves and to eat independently. A further consequence was *sexual disability* which contributed to a loss of sexual desire:

> Many people here are not independent enough to go to the toilet by themselves. So they can't get involved in sexual matters; they would even need help to masturbate. (Villar et al. 2014)

5.2.5.2 Environmental Factors

Environmental factors could alleviate or aggravate the impact of functional limitations. Facilities that were *accessible for people with disabilities* gave residents who suffered from functional limitations a sense of safety and allowed them to move around independently (Bourrett et al. 2002; Ball et al. 2004a; Cooney 2011; Speller and Tollee 2015). They had grab bars and non-skid surfacing in bath areas, electric doors, handrails on stairways and hallways, ramps and large doors for wheelchair accessibility. Facilities without such a design impeded residents' mobility and sometimes prevented the admission of disabled persons (Ball et al. 2004a, b). The *availability of assistive devices* like power wheelchairs or just walkers and canes also improved residents' mobility (Bourrett et al. 2002; Oosterveld-Vlug et al. 2013a). *Security systems* with door code numbers were intended to prevent residents from unauthorized leaving and restricted their mobility (Bourrett et al. 2002; Tuominen et al. 2016). In some facilities, *inconvenient beds* caused physical discomfort and increased the risk of falling due to their height (Chang 2013). *Noise* and *inappropriate room temperature* (i.e. either to warm or to cold) were a reason for sleep disturbances (Herrmann and Flick 2011; Heid et al. 2016).

Due to lack of financial resources facilities in developing countries were often not accessible for people with disabilities. They even had *problems getting medication* to treat their residents (Hweidi 1999; Teka and Adamek 2014). As a physician in a Jordanian nursing home told:

> Our financial capabilities can't allow us to buy all the medicine we need. Sometimes the Ministry of Health covers a part of our pharmaceutical needs, while other times they don't have them. (Hweidi 1999)

Some facilities that cared for the poor and needy were at least able to *distribute clothes* once a year (Teka and Adamek 2014).

A factor that influenced the satisfaction of food consumption was the *quality and quantity of meals* (Timonen and O'Dwyer 2009; Wright et al. 2010; Teka and Adamek 2014; Bollig et al. 2016). Facilities for the poor could only provide bare necessities. In the Ethiopian home, for example, meals consisted of "dabe" (a kind of bread) for breakfast, and "injera" (a sourdough-risen flatbread) at lunch time and dinner, while meat was served only three times per year (Teka and Adamek 2014). In contrast, the residents in wealthier countries had more choice and could enjoy better food - especially when their clients were affluent. An assisted living facility in the US, for example, offered regularly dishes like fresh salmon and turkey (Wright et al. 2010). Raske (2010) described a facility with an enabling garden that allowed residents to get fresh vegetables. Other nursing homes established a café that allowed residents to get snacks and cakes beside their regular meals (Andrews 2012).

An obstacle for the satisfaction of sexual desires was the *unavailability of double beds for couples* (Frankowski and Clark 2009; Bauer et al. 2013). Some facilities, however, offered married couples a *private room for occasional use* so that they could meet their desire (Bauer et al. 2013).

5.2.5.3 Care for Body-Related Needs

In case of functional limitations body-related needs had to be satisfied with the help of care. *Room cleaning* and washing of clothes and bedding in order to meet the need for hygiene were part of the basic services that some of the residents considered worth mentioning (Hweidi 1999; Rekawati et al. 2018). *Personal care* was provided by caregivers and included washing, dressing, and grooming (Grant et al. 1996; Hweidi 1999; Ball et al. 2004a; Hwang et al. 2013; Figueredo-Borda and Zabalegui-Yárnoz 2015; Koskenniemi et al. 2015). In case of severe limitations residents also needed *assistance for eating and toileting* (ibid.). Whereas these tasks were often performed by nursing assistants or even caregivers who had just received an on-the-job training, nurses were in charge of the *treatment of wounds* (Grant et al. 1996; Figueredo-Borda and Zabalegui-Yárnoz 2015; Gustavsson et al. 2015), the *monitoring of vital parameters* (Rekawati et al. 2018), and the distribution of *medication* (Hweidi 1999; Gustavsson et al. 2015). Some facilities were also concerned about *health promotion* and they offered exercises and educational programs about health and nutrition for their residents (Ball et al. 2004a, b; Stathi and Simey 2007; Rekawati et al. 2018).

Sometimes, however, residents observed also deficiencies of body-related care. They complained about a *lack of hygiene*, for example, when nurses distributed medication (Timonen and O'Dwyer 2009), and felt that staff *neglected mobilization and sleep promotion* (Bourrett et al. 2002; Herrmann and Flick 2011).

> It's a heck of a thing to say, but outside you may get more people to offer to help than in here. (Bourrett et al. 2002)

5.2.6 Behavioural and Attitudinal Reactions

Despite their declining health and functional limitations some residents made efforts to cope with this situation by activities. They participated in *exercises* if such a program was offered by the facility or they even tried to exercise alone (Ball et al. 2004b; Stathi and Simey 2007; Tsai and Tsai 2008; Behr et al. 2014; Cho et al. 2017; Rekawati et al. 2018)

> Every morning after breakfast, I go to the third floor to exercise, especially exercise appropriate for older people! (Cho et al. 2017)

Quite often, such exercises consisted of *walking* either inside the facility or—if permitted by physical abilities—outside of it (Cooney et al. 2009; Herrmann and Flick 2011; Taylor et al. 2014; Gustavsson et al. 2015). To prevent falls residents *used assistive devices* (Ball et al. 2004b). To protect their health residents were eager to comply with medical treatment and *took prescribed medication* (Ball et al. 2004a, b).

> I am very careful about taking my heart medicine. I'm gonna survive. (Ball et al. 2004b)

To satisfy their desire for physical rest and recovery, several residents said that they were *taking a nap* (Ball et al. 2004b).

Although residents made efforts to maintain their physical capacities, they were aware that on the long run their health was declining. In response, many of them told about their *acceptance of physical limitations* (Hjaltadóttir and Gustafsdóttir 2007; Walker and Curry 2007; Hutchinson et al. 2011; Nakrem et al. 2011; Falk et al. 2013; Behr et al. 2014; Taylor et al. 2014). "You just have to live with it" was a typical expression on dealing with this situation (Nakrem et al. 2011). Such acceptance allowed for a certain degree of satisfaction despite experienced limitations:

> You should be grateful for the degree of health you have, and you should also point it out to others that it's certainly something to be grateful for, to be able both to hear and see and not to be all that confused. (Hjaltadóttir and Gustafsdóttir 2007)

In order to protect their remaining health and to continue physical activities, some residents consciously *slowed down*, and avoided risky movements.

> I've got a sort of Ten Commandments which I tell myself, never hurry, never rush, never stretch for anything in case it's not there. (Hillcoat-Nalletamby 2014)

5.3 Long-Term Care Facilities and Social Orientations of Action

Moving into a long-term care facility meant a change of social relationships for older persons. Receiving care did not only concern the satisfaction of body-related needs, it also implied social relationships with the persons who provided care. Older persons had to find a new balance between their desire for self-reliance and their need to be cared for, but also between their tendencies to exert influence on others and to pay attention to their needs. Staying in a long-term care facility meant furthermore getting into close contact with other residents. At the same time contacts to family, neighbours, and friends outside became more difficult due to increased distance. These circumstances required them to establish a new balance between their desires for closeness and distance, but also between their tendencies to social adjustment and unconventionality. Table 5.4 provides an overview over the social orientations of action, the various degrees of their satisfaction, the factors that influence this satisfaction, and the behavioural and attitudinal reactions of the residents.

5.3.1 Self-Reliance Versus Being Cared for

When older persons experienced functional limitations they could either try to remain self-reliant or they could develop a desire to be cared for.

5.3.1.1 Self-Reliance

Despite their functional limitations, several residents still had a *desire for self-reliance* (Bourrett et al. 2002; Ball et al. 2004b; Murphy et al. 2007; Stathi and Simey 2007; Bradshaw et al. 2012; Oakes and Sheehan 2012; Behr et al. 2014;

Table 5.4 Social orientations of action, influencing factors, behavioural and attitudinal reactions

Orientations of action and their satisfaction	
Self-reliance	Desire for self-reliance
	Hesitantly accepting some help
	Ready to give up self-reliance
Satisfaction of self-reliance	Maintaining self-reliance
	Regain of self-reliance
	Loss of self-reliance in unfamiliar environment
	Learned helplessness
	Gradual loss of abilities
Being cared for	Selective compensation of limited abilities
	Seeking for comprehensive attention
	Desire for hands-on care
	Concern about getting medical treatment
	Desire to feel safe and protected
	Desire for family care
	Expecting to get additional support from families
Satisfaction of being cared for	Availability of service
	Attentiveness to residents' needs
	Comfort and relief from burden
	Getting medical care
	Receiving little extras
	Receiving care for medical needs
	Feeling supported and protected by roommates
	Receiving support from the family
	Gratefulness for receiving care
	Feeling neglected
	Inattentiveness to care recipients' needs
	Minimal care
	Independent against their will
	Fear of remaining without help
	Lack of medical care
	Fear of threats
	Lack of support by the own family
Exerting influence on others	Maintaining control
	Demanding attitude
	Desire to participate in decisions
	Having some choice
	Being informed over health condition
	Expecting the obedience of own children
	Expecting roommates to comply with social norms
	No objections to decisions
	Desired paternalism

(continued)

Table 5.4 (continued)

Satisfaction of exerting influence on others	Being in control of care
	Having choices
	Participating in decisions about care
	Exceptions of control
	Allowed to act according to own will under supervision
	Being exposed to surveillance
	Institutional fear
	Restricted by rules and routines
	Lack of choice
	Powerlessness
	Loss of control over family
	Being annoyed by roommates
Attention to the needs of others	Fear to be a burden on family
	Wanting to reduce burden on caregivers
	Showing tolerance
	Avoidance of conversation to prevent conflicts
Satisfaction of attention to the needs of others	Reduced burden on families
	Feeling to be a burden on caregivers
	Feeling guilty for neglecting marital duty
Social adjustment	Adaptation to unwritten rules
	Hiding sexual desires and inclinations
	Being polite and well-mannered
	Observance of table manners
Satisfaction of social adjustment	Feeling normal and in tune with social environment
	Sense of structure and inner order
	Feeling ashamed
Unconventionality	Reduced interest to conform to social standards
	Striving for individual liberty
	Searching a temporary escape
	Tendency to socially undesirable behaviour
	Aggressive self-assertion
Satisfaction of unconventionality	Gain of an individual lifestyle
	Allowed to do what they liked
	Having to suppress own needs
Closeness	Desire for social participation
	Maintaining contacts to friends outside
	Desire for contact with the family
	Interested in contacts with roommates
	Preference for close contacts
	Preference for shared rooms
	Searching for a female partner
	Contacts according to inclination
	Desire for positive relationship to staff

Table 5.4 (continued)

Satisfaction of closeness	Social participation
	Loss of social participation
	Succeeding in maintaining old contacts
	Loss of old contacts
	Positive relationship to family
	Limited or no contact to family
	Separated from spouse
	Grief due to loss of significant others
	Couples who enjoy their company
	New partnerships
	Restricted contacts between the sexes
	Positive relationships with roommates
	Sense of community
	New contacts as a substitute
	Gain of contact
	Experiencing relationships as friendly but superficial
	Lack of contacts with roommates
	Decline of social contacts
	Loneliness
Distance	Maintaining privacy
	Desire for temporary withdrawal
	Restricted desire for contact with other residents
	Distanced relationship with caregivers
	Inclined to complete disengagement
Satisfaction of distance	Protected privacy
	Intrusion of privacy by caregivers
	Disturbance of privacy by roommates
Influencing factors	
Physical condition	Functional limitations
	Loss of hearing
	Cognitive decline
Circumstances of life	Moving in by own decision
	Financial resources
	Forced to move in
Environmental factors	Type of accommodation
	Communal spaces
	Noise
	Privacy policy
	Visitation rules
	Connection between facility and environment
	Access to the internet
	Family influenced social relationships

(continued)

Table 5.4 (continued)

Care for social needs	*Task-orientation*
	Formal assessment
	Informal monitoring
	Planning care without the resident
	Discussing about the resident instead of with him
	Excluding residents from participation in decisions
	Imposing day structure and routines
	Repeated task performance
	Care as prescribed
	Lack of communication with residents
	Dominance of medical care
	Overprotection
	Safety regulations
	Education and control
	Bossy and rude behaviour
	Rough treatment
	Inattentiveness
	Reluctance to provide help
	Keeping distance
	Person-centred care
	Planning care with residents
	Agreements on care and safety rules
	Offering choices
	Adapting to wishes and needs
	Becoming familiar with personal routines
	Attentiveness to the residents
	Care in time
	Small favours
	Chat and small talk
	Reducing distance
	Developing a relationship of trust
	Persuading the resident
	Searching the dialogue
	Promoting self-reliance
	Respecting and protecting privacy
	Influencing social contacts between residents
	Attempts to select residents
	Discharge of residents
	Promoting the integration of newcomers
	Arranging contacts
	Facilitating communication
	Simulating real life situations
	Common meals
	Family-style service
	Seating arrangements
	Organizing joint activities

Table 5.4 (continued)

	Inviting residents
	Expectations to participate and socialize
	Restrictions on mutual visits
	Involving significant others
	Restricting visits from families and friends
	Preventing intimate relationships
	Providing discreet environments for intimate relationships
Behavioural and attitudinal reactions	*Towards caregivers*
	Asking for help
	Expressing appreciation
	Engaging in small talk
	Sharing private matters
	Demanding and complaining
	Racism
	Hiring additional staff
	Rejecting help
	Rejecting well-meant advices
	Resisting against care
	Giving in
	Subordination
	Avoiding complaints
	Towards roommates
	Engaging in conversation
	Showing affection
	Assistance and emotional support
	Forming groups
	Gossip
	Reprimanding
	Shunning persons with dementia or other impairments
	Quarrel
	Avoiding contact with all roommates
	Formal politeness
	Leaving sometimes the facility

Hillcoat-Nalletamby 2014; James et al. 2014; Taylor et al. 2014; Shin 2015; Speller and Tollee 2015; Tuominen et al. 2016). They did not want to receive help from others as they felt that such help restricted the independence and self-determination they had been used to throughout their life.

> I like to do things for myself. If I can do it myself, I'll do it myself. They're supposed to come in, in the morning and make me tea and make me toast and things like that, if I want it. But I'd much rather do it myself. (Hillcoat-Nalletamby 2014)

This attitude was particularly strong in assisted living facilities, but also nursing home residents expressed this desire. However, when the functional limitations increased, these residents *hesitantly accepted some help* (Nakrem et al. 2011*;* Shaw et al. 2016).

> I have health issues which are a little bit personal and I don't know that I can handle at the moment somebody doing what I might need help with and I would rather struggle on. Now that might sound like pride, it's not, it's embarrassment. […] So I'm at a bit of a crossroads I think. I would like not to have to change anything because I fiercely want to keep my independence anyway. But I feel worried about that, if I am going to deteriorate anymore and I do need some help, erm, coming to terms with having what feels a little bit invasive. (Shaw et al. 2016)

At the end, they were *ready to give up self-reliance* and to receive help from caregivers.

> You push your pride aside and come to the realisation that you do need it [assistance] and do not object to it. That's the first thing. Once you've done that I'd say you'd be prepared to go, accept the type of assistance they [staff] think desirable (Taylor et al. 2014)

5.3.1.2 Satisfaction of Self-Reliance

At least for some time, several residents succeeded in *maintaining their self-reliance* (Bourrett et al. 2002; Ball et al. 2004b; Murphy et al. 2007; Wright et al. 2010; Cooney 2011; Martinsson et al. 2013; Oosterveld-Vlug et al. 2013a; Palacios-Ceña et al. 2013; Hillcoat-Nalletamby 2014; Minney and Ranzijn 2016).

> I basically look after myself. I can do everything myself. I'm not like some of the people here; I am capable of looking after myself. (Hillcoat-Nalletamby 2014)

Self-reliance, however, could have different meanings, depending on the capabilities of the older persons. Residents in nursing homes were already satisfied, if they were still able to move around independently—even if they had to use assistive devices (Oosterveld-Vlug et al. 2013a). For others, self-reliance implied the ability for self-care despite difficulties. One older woman, for example, told how she spent "four hours just trying to get myself clean and cutting my fingernails and rolling my hair and just things like that" (Ball et al. 2004b). Others were satisfied if they could eat without help (Palacios-Ceña et al. 2013). Some residents in assisted living facilities even enjoyed performing household task in their own room.

> I've got macular degeneration as I said, but I'm still fairly independent. I don't require help to do anything - I even make my own bed every morning, and I don't need any help of that nature. I've got a lot of independence and that's one of the main things here that I'm enjoying (Minney and Ranzijn 2016)

Sometimes residents in nursing homes even reported a *regain of self-reliance* if they had a chance to exercise and were encouraged to do so (Stathi and Simey 2007; Oosterveld-Vlug et al. 2013a):

> When I came here, I couldn't walk. But being left in my own, in my own room, I was determined to walk round the room and then the corridor, and things like that. (Stathi and Simey 2007)

Others, however, told about a certain *loss of self-reliance in the unfamiliar environment* of the facility after they moved in (Shaw et al. 2016). They felt anxious about leaving the place because they did not know their way around and preferred to stay inside.

More often residents felt *incapacitated by security rules* that restricted their independence and range of activities (Bourrett et al. 2002; Ball et al. 2004b; Dobbs 2004; Cho et al. 2017; Timonen and O'Dwyer 2009; Oakes and Sheehan 2012; Palacios-Ceña et al. 2016a). This occurred not only in nursing homes but also in assisted living facilities which emphasized resident's autonomy and self-responsibility.

> They won't let me shower by myself, but I can shower by myself. They won't let me go in there and shower just alone. (Ball et al. 2004b)

> I feel confined here. I really want to go out, but staff don't let me out because it's cold out there now. I understand that. They may worry about any possible injuries, but I am still disappointed with the fact that we need their permission to get out. (Cho et al. 2017)

Overprotective care even induced *learned helplessness* and residents gave up performing self-care because they were given no chance to do so (Koch-Straube 2003; Ball et al. 2004b; Hellström and Sarvimäki 2007a, b; Murphy et al. 2007; Behr et al. 2013; Hillcoat-Nalletamby 2014). Their attitudinal change became sometimes apparent in the interviews:

> *Interviewer:* So, you don't have the option of getting yourself washed and dressed?
> *Respondent:* Oh no, no.
> *Interviewer:* Do you think you could?
> *Respondent:* I'd have to have help, I think, especially to get dressed but I think I could wash myself, the way they do. (Hillcoat-Nalletamby 2014)

As a result of overprotective care residents experienced a *gradual decline of independent self-care* until they became completely care-dependent (Saunders and Heliker 2008; Hutchinson et al. 2011; Falk et al. 2013; Iden et al. 2015; Shaw et al. 2016; Cho et al. 2017).

> It's hard for me to move [by myself]. I need others' help to stand up and [sit] down or go to [the] hospital. (Cho et al. 2017)

> I am often sad because I have to wear diapers and need help to use the bathroom. But I don't like it when my diapers are wet and I'm completely dependent on care. (Iden et al. 2015)

5.3.1.3 Being Cared for

Other residents were less inclined to maintain their self-reliance and did not hesitate to accept care when they experienced functional limitations. Some of them just wanted to get a *selective compensation of limited abilities* (Ball et al. 2004b; Bergland and Kirkevold 2006; Falk et al. 2013; Hillcoat-Nalletamby 2014; Melin-Johansson et al. 2014; Taylor et al. 2014; Speller and Tollee 2015; Koppitz et al. 2017). A relief of burdensome activities made life easier and allowed them to focus on other things of more importance. They wanted to remain independent to some extent while receiving care and support at the same time:

> The arrangements are better for me, like take shopping. I can do it independently… the energy that I used to waste with trying to shop and cook, it's taken from me now, I don't

> have to do that, I only have to think about breakfast or tea and that's easy (Hillcoat-Nalletamby 2014)

Others were *seeking for comprehensive attention* (Ball et al. 2004b; Josat 2005; Robichaud et al. 2006; Hjaltadóttir and Gustafsdóttir 2007; Oakes and Sheehan 2012; Bollig et al. 2016; Christov 2016; Heid et al. 2016). They wanted to rely on their caregivers and expected them to have time and to be attentive to their needs. As a family member said in place of the residents:

> A good caregiver is the one who pays attention to the resident's needs, listens, gives exclusive time to the resident (Robichaud et al. 2006)

Some even tried to absorb the attention of others by monotonous complaints (Christov 2016). Seeking for attention implied a *desire for hands-on care* (Grando et al. 2000; Ball et al. 2004b; Hwang et al. 2013; Chuang et al. 2015). Residents wanted caregivers to respond promptly to their needs of daily living like eating, toileting, or hygiene.

> I appreciate nurses giving me my medicine, food, desserts, and soft drinks regularly…and changing my diaper as soon as possible (Hwang et al. 2013)

Some residents also mentioned their *concern about getting medical treatment* (Grando et al. 2000; Nakrem et al. 2011; Hwang et al. 2013).

> When I am sick, they should take action….such as checking my blood pressure and temperature, helping me to relax, or taking me to see a doctor. (Hwang et al. 2013)

Beside such concrete help residents had a *desire to feel safe and protected* (Ball et al. 2004b; Robichaud et al. 2006; Hjaltadóttir and Gustafsdóttir 2007; Stathi and Simey 2007; Nakrem et al. 2011; Falk et al. 2013; Schenk et al. 2013; Taylor et al. 2014; Chuang et al. 2015; Shin 2015; Koppitz et al. 2017). Being aware of certain risks for their health they just wanted someone to be there and look after them in case of any trouble.

> That you feel more secure, you know, I feel, I'm calmer inside […] That I'm um, well, looked after, let's say, or protected […] Because when, because I often get palpitations (Schenk et al. 2013)

This desire was one of the reasons for moving into a long-term care facility:

> I'm all alone, and my people live an hour each ride in a car away. Can't expect to call on them, and things don't happen in the day, they happen in the night when you cannot get a doctor outside to come and visit you. (Stathi and Simey 2007)

Older persons from more traditional cultures where care was perceived to be a duty of the family did not want to receive such support and security in long-term care facilities. They had instead a *desire for family care* (Shin 2008; Chuang and Abbey 2009; Andrews 2012; Shrestha and Zarit 2012; Chang 2013). As one older Korean woman said:

> It is natural for old people to live with their first son's family and be cared by them. It is natural. (Shin 2008)

In Western countries where institutional care was culturally more acceptable residents in long-term care facilities nevertheless *expected to get additional support from their families* like occasional shopping or transportation (Park et al. 2012; Tompkins et al. 2012; Hillcoat-Nalletamby 2014).

5.3.1.4 Satisfaction of Being Cared for

The satisfaction of the desire for being cared for had several aspects. It referred to the *availability of service* (Andersson et al. 2007; Bland 2007; Tsai and Tsai 2008; Wright et al. 2010; Nakrem et al. 2011; Figueredo-Borda and Zabalegui-Yárnoz 2015; Koppitz et al. 2017; Rekawati et al. 2018) and to *caregivers' attentiveness to residents' needs* (Ball et al. 2004a; Bergland and Kirkevold 2006; Bland 2007; Jordan 2010; Wright et al. 2010; Nakrem et al. 2011; Hwang et al. 2013; Donnelly and MacEntee 2016; Lung and Liu 2016; Koppitz et al. 2017).

> They wash and dress me in the morning. They clean my flat. They do my laundry. If I need them to sort of open a window or close a window, they will come and do that. I can't reach some of them, you see. I have my breakfast, but they do all my ironing, washing, that type of thing. And they look after me; make sure I've taken my insulin. (Wright et al. 2010)

What residents appreciated most was that caregivers met their needs without having to tell them:

> They make every attempt; I can't imagine what else they can do. They make every attempt to meet my needs and to even anticipate my needs. (Jordan 2010)

> We do not have to talk so much, because she knows exactly how I want to be helped. I am so glad I do not have to explain (Bergland and Kirkevold 2006)

Such care provided *comfort and relief from burden* (Iwasiw et al. 1996; Iwasiw et al. 2003; Walker and Curry 2007; Tsai and Tsai 2008; Cheng et al. 2011; Nakrem et al. 2013; James et al. 2014; Teka and Adamek 2014; Minney and Ranzijn 2016; Shaw et al. 2016; Cho et al. 2017).

> This place is better than my house … here, I just eat and sleep! Everything is done by staff, so I feel very relaxed (Cho et al. 2017)

At the same time, these residents felt protected and safe because there was always someone there to help them in case of problems. (Iwasiw et al. 1996; Andersson et al. 2007; Tsai and Tsai 2008; Jordan 2010; Cooney 2011; Oakes and Sheehan 2012; Nakrem et al. 2013; Hillcoat-Nalletamby 2014; Melin-Johansson et al. 2014; Oosterveld-Vlug et al. 2014; Teka and Adamek 2014; Chuang et al. 2015; Shin 2015; Minney and Ranzijn 2016; Shaw et al. 2016)

> It is very safe to live in this place. There are a lot of nurses to take care of me. There was nobody at my home during the day. My son was afraid of me falling again at home and sent me here. I have good care in this place. (Tsai and Tsai 2008)

Some residents also told how their feeling of being cared for was increased when they *received little extras* (Thomas et al. 2013; Lung and Liu 2016)

> I feel that the nursing assistants care about me.… Sometimes I say I'd love to have some ginger…. I get a small pack of ginger the next day from the nursing assistants …. They know what I like to eat… because they see what I eat daily…. Also, I have to eat something before I go to sleep because our dinner is early. So I eat bread, biscuits, etc. Since they know this, they always drop some food off for me. (Lung and Liu 2016)

Others were satisfied because they *received care for their medical needs* and were treated according to the prescriptions of physicians (Wu and Barker 2008; Boggatz et al. 2009). If they suffered from chronic illness, staying in a nursing home could imply ease access to necessary treatment as in the case of an older woman in Cairo who needed haemodialysis and would have been unable to reach the medical centre due to lack of suitable transportation (Boggatz et al. 2009). Residents in assisted living facilities mentioned sometimes that they also *felt supported and protected by their roommates* because they provided occasional help and checked on each other:

> My eyesight is so bad. A lot of time I ask her [a female resident], when I'm going to church on Sunday…. I have to ask her, you know, do I need to wear this? Or do I need to wear something else or whatever. (Park et al. 2013)

> Today, someone asked for me why I was not here. […]You notice who is missing and then you worry because you don't know that he is missing because he is sick or in the hospital or something. (ibid.)

Furthermore, the desire to be cared for was met when residents *received support from their family* (Iwasiw et al. 1996; Ball et al. 2000; Ball et al. 2004a; Kennedy et al. 2005; Bland 2007; Williams and Warren 2009; Cheng et al. 2011; Tompkins et al. 2012; Martinsson et al. 2013; Thomas et al. 2013; Hillcoat-Nalletamby 2014; Adra et al. 2015; Gustavsson et al. 2015). Family members provided financial support, took residents out for social activities, and were engaged in a range of care tasks such as laundering, shopping, and sometimes even personal care.

> I'm very low care because I have some of my family who help me when needed …. My daughter helps me sometimes I might want my back washed … she helps with cleaning as well (Hillcoat-Nalletamby 2014)

Beside such direct support, family members also provided indirect support by giving advices to staff on how to care for the resident. They informed them, for example, about the resident's preferences regarding food—especially when caregivers were not familiar with the cultural background and habits of the older person:

> No yogurt or ice cream. She doesn't like cold foods. She is afraid of cold food. The box milk [carton] she doesn't like. I think it's a habit. The elderly Chinese people, they don't like cold. Mom will spit it out. (Wu and Barker 2008)

In sum, a number of residents expressed their *gratefulness for receiving care* (Heliker and Scholler-Jaquish 2006; Nakrem et al. 2011, 2013; Oosterveld-Vlug et al. 2014; Bollig et al. 2016)

> I have a place to lay my head down at night and three meals a day, and a van gets me to church on Sunday, and so I'm just thankful. (Heliker and Scholler-Jaquish 2006)

Some authors, however, point out that such gratefulness should not be confused with satisfaction (Sidenvall 1999), because basic care needs may be met, while other social and identity-related needs remain unsatisfied, and residents may respond according to social desirability knowing that they depend on the care provided by the facility—even if it was less satisfying. Many other residents in fact reported that their desire to be cared for was not satisfied and they *felt neglected* by their caregivers (Grau et al. 1995; Bowers et al. 2001; Coughlan and Ward 2007; Timonen and O'Dwyer 2009; Jordan 2010; Cooney 2011; Nakrem et al. 2011; Falk et al. 2013; Oosterveld-Vlug et al. 2013a, b; James et al. 2014; Taylor et al. 2014; Bollig et al. 2016; Tuominen et al. 2016). Having to wait when they asked for help because the staff did not listen, was not concerned, or had no time was a common complaint.

> We do have much waiting time… if there is something [you need] … they tell you that you just have to call, just call … so everything will be done, but it is not like that … it takes time. For example, if I sit here and eat breakfast, I just need to call when I am done. Then you may sit a long time… a very long time before they think that I am done, and I have to wait for them to come… (Bollig et al. 2016)

This was particularly embarrassing when residents had urgent needs:

> I tell them I have to go to the bathroom and I can't wait and they still don't come. It's cruel to make someone wait when they know it'll mean an accident. Sometimes I can't go and they get so disgusted, and even if they don't, I feel bad. I'm taking up their time. (Bowers et al. 2001)

> Often in our day room, a person becomes unwell and there's no nurse available […] I'm not able to get up and walk and go out for a nurse and I keep shouting for a nurse and a nurse can't come. (Timonen and O'Dwyer 2009)

If, however, caregivers performed their tasks, they did so in a hurry and were *inattentive to the care recipient's needs* (Andersson et al. 2007; Westin and Danielson 2007; Jordan 2010; Cheng et al. 2011; Hwang et al. 2013; Donnelly and MacEntee 2016)

> They approach you in such a way that you feel you are actually being ignored – yes, you do not exist – you are just like a ghost, nothing else…It is awful, I tell you. It is so cruel. (Westin and Danielson 2007)

Lack of attention was associated with *minimal care* that avoided effort and left basic needs unsatisfied (Grau et al. 1995; Nakrem et al. 2013; Donnelly and MacEntee 2016; Bollig et al. 2016; Heid et al. 2016):

> I've always got pads on … To begin with, I thought it was absolutely foul … In the hospital they gave you the bedpan, but they don't give you that here. They don't approve of that, so what can I do … you lie in your own filth, but then they come and take the dirty pad off, put a clean one on, and away they go again. (Donnelly and MacEntee 2016)

In some facilities the restricted number of baths per week were a reason for complaints by residents:

> I don't know any woman who wants to go without a bath for one week. I was quite horrified that we were only going to get it once a week. (ibid.)

Such minimal care seemed to accelerate the physical decline of the residents. Regarding her roommates one older woman observed:

> I think they lay in bed too much. There aren't enough people and it occurs to me that they should be giving more help to them. (Nakrem et al. 2013)

In some assisted living facilities, the desire to be cared for was not satisfied, when residents were forced to remain *independent against their will*. As they were told, it was part of the institutions philosophy to provide care as minimal as possible (Wright et al. 2010; Oakes and Sheehan 2012).

> I was going to have a carer to put me to bed and they wouldn't help me. I said to one of them, 'Rita will you help me?' She says: 'We're here to make you independent.' (Wright et al. 2010)

Residents in extra care houses that had no night-time staff also told about their *fear of remaining without help* at night in case there should be any trouble (Wright et al. 2010). Residents in nursing homes complained sometimes about a *lack of medical care* (Chang 2013; Falk et al. 2013; Teka and Adamek 2014). While such complaints are understandable for facilities in developing countries which lack financial resources, this is all the more surprising for homes in developed countries:

> Well, since I've been here, everybody has told me: 'This is not a hospital but only a nursing home', when I feel sick and ask for help. Of course, I know I'm in a nursing home. But I really feel pain… (Silence) When I'm in pain and exhausted, I should have an injection… When I feel bad, I want to have an injection, but they seem to neglect me. (Chang 2013)

Another issue that prevented the satisfaction of the desire to be cared for was the *fear of threats* that allegedly or actually existed in the facility. Sometimes this fear was rather unspecific and due to the unfamiliar environment (Iwasiw et al. 1996; Timonen and O'Dwyer 2009). Others were afraid of a rude treatment by caregivers (Fiveash 1998; Bland 2007). But also roommates were a source of threat if they showed disruptive behaviour (Fiveash 1998; Hjaltadóttir and Gustafsdóttir 2007; Frankowski and Clark 2009) or were supposed to steal other residents' properties (Koch-Straube 2003; Tsai and Tsai 2008).

> I was frightened. I awoke one night and this man was standing at the end of my bed, looking at me. He had scars and sores in his face, a bandage over his ear. I'd never seen him before. I don't like to complain, but it's very frightening. (Fiveash 1998)

A final problem that had a negative impact on the feeling of being cared for was the *lack of support by the own family* (Shin 2008; Shrestha and Zarit 2012; Chang 2013;

Schenk et al. 2013; Teka and Adamek 2014; Mohammadinia et al. 2017). Some residents received only occasional visits from their relatives, whereas others felt that their family wanted to get rid of them and forced them to stay in a long-term care facility. This feeling was particularly strong among residents who had grown up in a culture that valued family care:

> My children didn't let me stay at their home. That's why I am here. This is not what I wanted. They forced me to come here. I said nothing. I was dragged like the dead when they wanted me to go. What should I do? So, I have been suffering until now… (Chang 2013)

> My daughter's husband is dead, and we could live together but as she is very wicked, she relocated me here, and I think she has forgotten me. (Mohammadinia et al. 2017)

5.3.2 Exerting Influence on Others Versus Attention to the Needs of Others

When older persons needed care and moved into a long-term care facility they could either try to influence or even control caregivers and roommates in order to enforce their will and maintain their self-determination, or they could pay attention to the needs of others and refrain from demands.

5.3.2.1 Exerting Influence

Since they were used to determining their own lives residents understandably had a *desire to maintain control* over persons they depended on (Shin 2008; Tuominen et al. 2016). Some of them had a *demanding attitude* regarding care (Ball et al. 2004b, 2009; Bowers et al. 2001; Iwasiw et al. 2003; Dobbs 2004; Williams and Warren 2009; Cooney 2011; Oosterveld-Vlug et al. 2014; Roberts and Bowers 2015). They perceived care as a service that had to be delivered according to their expectations.

> I'm really used to directing my own care … And that doesn't always go over real well with people in a place like this because I'm used to telling people what to do and having it done when I tell them to do it. (Roberts and Bowers 2015)

> To stay like in a hotel, they should serve me. (Boggatz et al. 2009)

Since they paid for the care they received they evaluated it according to what they believed to be the value of its price. If caregivers failed to meet their expectations they started complaining about the lack of service and their inabilities.

> When I'm paying so much I should have more to say. I'm paying good money to stay here, I should have better service. I pay $3000 a month and I can't even get a glass of water when I want it. (Bowers et al. 2001)

> I don't know why they don't train them better…[they] can't even figure out the simplest things (ibid.)

> [They are] so unorganized, I mean, [they] use 100 steps to do something that would take someone with more common sense only 10. (ibid.)

To enforce their will they reprimanded their caregivers or they complained about them to their supervisors (Bowers et al. 2001; Oosterveld-Vlug et al. 2014). Such a demanding attitude was found in some nursing homes (Iwasiw et al. 2003), but it mainly existed in assisted living facilities for upper-class residents that subscribed to a philosophy of consumer autonomy. In such a facility researchers observed how caregivers were treated like waitresses in a restaurant when they served the meals (Dobbs 2004) and caregivers complained about the bossy behaviour of the residents (Ball et al. 2009; Williams and Warren 2009). As one worker said, "Some of them won't open up at all. They are like, 'Get the trash and go.'"(Ball et al. 2009).

Other residents had a less demanding attitude and were willing to accept some restrictions due to care, but they nevertheless had the *desire to participate in decisions* regarding their own care (Murphy et al. 2007; Nakrem et al. 2013; Behr et al. 2013; Falk et al. 2013; Schenk et al. 2013). One resident recalled an event where she had to express this desire:

> 'So, Mrs A, today, today we're going to have a shower'. I look, and say what, why today? I say, no, I say, not with me. I [laughing] I say, not today, I'm not showering. I say, I'd like to be told at least one day in advance that we're having a shower tomorrow, and at about what time. (Schenk et al. 2013)

Despite their readiness to comply with the necessities of care, these residents wanted to *have some choice* and decide about certain aspects of their daily life that were of importance for them (Iwasiw et al. 1996; Murphy et al. 2007; Bowers et al. 2009; Cooney et al. 2009; Chin and Quine 2012; Oosterveld-Vlug et al. 2013a; Palacios-Ceña et al. 2013; Tuominen et al. 2016). Desired decisions were mainly about small things like how they can spend their day and have their meals, where they can walk around, or with whom they can talk and interact.

> Sometimes I feel like eating in my room, being able to choose what to eat…It makes me feel like I am at the wheel. (Palacios-Ceña et al. 2013)

Another aspect regarding control concerned their *desire to be informed over their health condition* because it allowed understanding why a certain treatment was required (Schenk et al. 2013; Chuang et al. 2015)

> It is very important to know my present conditions and the disease I have now (Chuang et al. 2015)

Residents' tendency to exert control also concerned the relationship to their family. In cultures where care for older persons was considered to be a duty of the family they *expected the obedience of their children* and wanted to be cared for by them instead of staying in a nursing home:

> When one begets a son, one expects the son to grow, be loving and disciplined. One also expects the daughter-in-law, too, to be disciplined. (Shrestha and Zarit 2012)

The desire to maintain control became furthermore apparent in the relationships to roommates. Older persons *expected them to comply with social norms* and good manners (Sidenvall 1999; Hubbard et al. 2003; Koch-Straube 2003; Behr et al. 2013; Nakrem et al. 2013; Palacios-Ceña et al. 2013; Christov 2016; Naess et al. 2016). Some were annoyed if someone dirtied the toilets. Others felt disturbed by residents who were messing with their food, burping, yelling, or crying out in pain and reprimanded them for such misbehaviour. In some cases they made staff to sanction what they considered to be inappropriate behaviour as it was experienced by one older woman who had just moved into a facility.

> I got here 2 months ago and sat where I was told. A lady said that I was rude because I didn't pray before eating…She and her friends talked to the nurse assistant and the next day I was moved. (Palacios-Ceña et al. 2013)

Some residents even became aggressive if a roommate got on their nerves. Hubbard et al. (2003) report an incidence where a female resident repeatedly asked to go to the toilet until another resident shouted: "You're not needing the toilet at all; go and give her a slap in the mouth". Several residents were also not inclined to tolerate an open expression of sexuality by others, especially by homosexuals, as this contradicted their idea of morality (Donaldson et al. 2014).

Not every resident, however, wanted to stay in control and to exert influence on others. Some were of the opinion that care was not their business, but the job of the caregivers. Consequently, they had *no objections to their decisions*, did what they were told, and did not feel like they were losing control (Murphy et al. 2007; Nakrem et al. 2011; Taylor et al. 2014)

> At my age I don't bother I do whatever the girls tell me to do. (Murphy et al. 2007)

> 'I'll say if they want to [assist], that's their business, not mine' (Taylor et al. 2014)

Others showed an attitude that might be labelled as *desired paternalism* (Bowers et al. 2009; Nakrem et al. 2011; Oosterveld-Vlug et al. 2013b; Melin-Johansson et al. 2014). They believed that it was best to let caregivers make decisions about daily matters such what to eat or how to care for their body, since they thought others were more knowledgeable on these matters. Some were even convinced that they did not have to tell caregivers their wishes because they would know them anyway.

> Staff know what I like and don't like. (Bowers et al. 2009)

This renouncement of exerting influence was associated with the desire for being cared for.

5.3.2.2 Satisfaction of Exerting Influence

Some residents were able to exert influence on the care received. *Being in control of care* meant that they were allowed to decide by themselves to move into a long-term care facility (Koppitz et al. 2017) and that they could determine their life although they were dependent on the help of others (Ball et al. 2004b; Falk et al. 2013).

> Oh no, I'm not sorry one bit that I'm in a wheelchair and can't cope on my own. I'm still the captain of this ship, and I do whatever I want… I just need a little bit of support. (Falk et al. 2013)

The feeling of being in control implied that residents actually *had choices* (Murphy et al. 2007; Cooney et al. 2009; Cheng et al. 2011; Philpin et al. 2011; Raske 2010; Oosterveld-Vlug et al. 2013a; Palacios-Ceña et al. 2013; Andrew and Wilson 2014; Gustavsson et al. 2015; Minney and Ranzijn 2016; Tuominen et al. 2016). Such choices concerned the time to eat or sleep or the activities during the day. Flexible routines allowed accommodating residents' wishes.

> I can go to bed anytime that I like but after 10 suits me, I come in and look at my own television. (Cooney et al. 2009)

> I can do my own things leisurely – I don't have to stop my tasks suddenly. They (nurses) come to me and tell that it's coffee time and you can come to the living room when you are ready. I don't have to go there immediately. (Koskenniemi et al. 2015)

The choice was satisfactory if the facilities could offer a wide range of recreational activities (Cooney et al. 2009; Raske 2010). It was further enhanced if there was a café on the grounds that allowed for a certain variety of food (Andrew and Wilson 2014). The range of choice was, however, determined to some extent by the financial resources of the residents as not everybody could afford to move into facilities offering such amenities (Bowers et al. 2009).

Having choices depended furthermore on the actual possibility to *participate in decisions about care* (Murphy et al. 2007; Oosterveld-Vlug et al. 2013a; Koppitz et al. 2017).

> That has got better over time, them respecting your wishes. For example, how I want to be washed, the fact that I don't always want to take a shower, that I don't always want to eat in the dining room. (Oosterveld-Vlug et al. 2013a)

Other residents felt that there were some *exceptions to their independence* that seemed, however, to be acceptable. As one of them told:

> I can decide almost everything here – except… watching the time… the meals and such (Nakrem et al. 2013).

Residents with a risk to fall were only *allowed to act according to their own will under supervision*:

> I go out. Sometimes in the summer time I go down to the shops, but I'm not allowed out on my own. I have to get a nurse to come with me and she goes with me down to do the shopping and then we come back home again. (Cooney et al. 2009)

Other residents had a less favourable perception of such safety rules. They rather *felt exposed to surveillance*. In some facilities they were expected to wear an alarm (Andersson et al. 2007), in others they needed permission to go outside (Hweidi 1999). Some residents were annoyed by the permanent observation even in the night and they felt restricted in their freedom:

> They have some idiots running around at night checking out [the residents]… I had a man [staff] come in here about 2 o'clock in the morning. I said, 'What do you want?' He said, 'I wanted to make sure you're breathing.' It's so idiotic. I don't know who runs this place, but there isn't much brains attached to it as far as I'm concerned. They do silly things like that. If you're dead, you're dead and that's all there is to it. (Iwasiw et al. 2003)

In assisted living facilities such close monitoring of the residents could result in an atmosphere of *institutional fear* (Kuhn 2008; Warren and Williams 2008; Williams and Warren 2008, 2009; Zimmerman et al. 2016). Those who were still able to live independently were aware that staff was monitoring the development of their physical limitations and had the power to decide who should be transferred to a nursing home where they would eventually lose their self-determination. To avoid this loss, residents tried to hide their conditions, pretended to be healthy and even *participated in activities against their liking* because they were afraid that non-participation would be interpreted as a loss of abilities:

> I do what they ask me to do. […] If you can't do it you gotta get out of here (Williams and Warren 2008)

Paradoxically, assisted living, which was supposed to support independence, became a place where this very independence was subject to control with the intention of promoting it.

Residents in nursing homes who were due to their functional limitations more dependent on care felt *restricted by rules and routines* of the facility (Fiveash 1998; Iwasiw et al. 2003; Bourrett et al. 2002; Heliker and Scholler-Jaquish 2006; Bland 2007; Murphy et al. 2007; Tucket 2007; Tsai and Tsai 2008; Cooney et al. 2009; Timonen and O'Dwyer 2009; Chin and Quine 2012; Hwang et al. 2013; Martinsson et al. 2013; Nakrem et al. 2013; Oosterveld-Vlug et al. 2014; Villar et al. 2014; Tuominen et al. 2016; Chuang and Abbey 2009; Gustavsson et al. 2015; Bollig et al. 2016; Donnelly and MacEntee 2016; Heid et al. 2016; Naess et al. 2016; Cho et al. 2017; Mohammadinia et al. 2017; Koppitz et al. 2017; Rahayu et al. 2018). They felt that everything was regulated: the time to awake, to eat, and to sleep, the amount of their food, their daily activities, and their hygiene. Their own wishes were overruled by standards of care and if they wanted to complain staff simply would not listen.

> Well, they are limited by the ways things are organized, by the rules. You have to follow what others do, now it's time for lunch, now it's time to go to the bathroom… You're not free, it's not like being at home. (Villar et al. 2014)

> In the dining room, they like you to have your own place. You can't change places, and they have rules. You can't do this; you can't do that. (Heliker and Scholler-Jaquish 2006)

> My opinions are not heard, and nothing has been fixed… the staff [members] just follow their rules… even though I say something to them, they don't listen. (Cho et al. 2017)

Due to these imposed rules and routines, residents felt that there was a *lack of choice*, except for small details that depend on the consent of their caregivers (Dobbs 2004; Chin and Quine 2012; Heid et al. 2016).

> I'm not satisfied because I do not have any choice. That's what I mean, if they ask you first, then we talk then I would be satisfied. Don't come and say: 'This is what I am going to do.' Of course I would say: 'Why? Do we have any other options beside this?' (Heid et al. 2016)

In the long run, such lack of choice resulted in a feeling of *powerlessness* (Grant et al. 1996; Fiveash 1998; Bourrett et al. 2002; Iwasiw et al. 2003; Koch-Straube 2003; Andersson et al. 2007; Bland 2007; Hellström and Sarvimäki 2007a, b; Tucket 2007; Westin and Danielson 2007; Svidén et al. 2009; Timonen and O'Dwyer 2009; Hutchinson et al. 2011; Nakrem et al. 2011, 2013; Hwang et al. 2013; Oosterveld-Vlug et al. 2014; Iden et al. 2015; Tuominen et al. 2016; Bollig et al. 2016; Donnelly and MacEntee 2016).

As they perceived it, they were forced to obey to their caregivers, and because they saw no chance to change this situation they felt imprisoned.

> I am a victim. I can't decide anything for myself. I don't have any influence … everything goes according to my contact person's schedule. (Hellström and Sarvimäki 2007a, b)

Some residents even described how they were intimated by the rude behaviour of caregivers.

> If the mean nurse is on duty, I don't dare to call for help. (Iden et al. 2015)

The feeling of powerlessness was sometimes reinforced by regulations that aimed to protect the rights of the residents:

> There's quite a few things that need to be straightened out … We have a Residents' Council … that's phony … nothing happens from it. (Iwasiw et al. 2003)

If caregivers abused their power they could even drive residents into isolation and emotional decline as observed by one study participant:

> There is a lady here who sat at my table for lunch. She had one leg and was blind & deaf …. One day she started using her hands to feed herself instead of using the spoon …. I started to feed her …. One day a Sister (registered nurse) saw this happening and said she'd have to be a complete feed, so they moved her …. She (resident) hasn't spoken to any of us since … she has gone right back into herself and won't speak to anyone any more even the nurses. A sad case I think. We asked for her to be moved back to our table, but were told, "No can do". We (residents) have to do as we are told. (Tucket 2007)

Such feelings of powerlessness were aggravated if residents had been forced to move into the facility by their family (Iwasiw et al. 1996; Boggatz et al. 2009; Wu et al. 2009; Chang 2013; Walker and Paliadelis 2016: Koppitz et al. 2017) and lost control over their possessions and money (Shin 2008). For older persons from traditional cultures, where care was perceived to be a duty of the children, such a forced move into a long-term care facility also meant a *loss of control over their family* (Boggatz et al. 2009; Shrestha and Zarit 2012; Mohammadinia et al. 2017; Wu et al. 2009). They felt expelled from their own home and accused their children of being selfish since they apparently rejected to care for their parents as they had once cared for them when they were children. An older woman from Egypt, for example, expressed her anger about her “ungrateful” daughter-in-law:

> The problem was she doesn’t like anyone else to share with her the flat. She wants to be in the flat with her children only. She said to me, there is no room. (Boggatz et al. 2009)

In her anger, she added that the only benefit of staying in the nursing was to “get rid of her”. Older women from Taiwan told how they were taken to the nursing home without being informed what was going to happen, so that they had no choice but to accept the decision their children had made:

> I didn’t know what was happening! He (the son) said he would like to take me for a ride… I didn’t know it before I came here. My son brought me here and he told me to take a rest and relax here. (Wu et al. 2009)

With regard to their roommates, residents were often unable to assert their expectations of compliance with social standards. As a consequence, they felt *annoyed by roommates*. Sometimes such annoyance was caused by inappropriate manners and caused disgust (Sidenvall et al. 1994; Iwasiw 1996; Fiveash 1998; Hubbard et al. 2003; Ball et al. 2004a; Dobbs 2004; Shin 2008; Behr et al. 2013; Chang 2013; Nakrem et al. 2013; Naess et al. 2016; Palacios-Ceña et al. 2013; Tuominen et al. 2016).

> The man in front of me spat in his hand and smeared it out on the table in front of me. They cough up and just smear it on the table..,. lt is rather terrible, in fact. (Sidenvall et al. 1994)

> Look at him! He poops m the bed and eats in bed. Just watching him makes me sad. (Shin 2008)

> When she was having a meal, she wanted to go to the toilet. See, you have to go before or after. She got up one day and said: ‘You don’t let me go now.’ She said: ‘I’ll piss on the floor’. (Fiveash 1998)

In other cases the behaviour of roommates violated others residents’ privacy (Walker and Paliadelis 2016) or it was disruptive, openly aggressive, and resulted in conflicts (Fiveash 1998; Hubbard et al. 2003; Boggatz et al. 2009; Curle and Keller 2010; Nakrem et al. 2013; Teka and Adamek 2014; Roberts and Bowers 2015; Cho et al. 2017).

> One day I had her dancing here, happy as Larry. She went over there and pulled the plugs out of the TV set. She threw everything off the chair and I had my bandages in the end of my bed ‘cause it had been tea time and I put them down there. She threw them all on the floor. (Fiveash 1998)

> At times, residents in front of me who have dementia have asked me: ‘Why are you still alive?’ I answered: ‘How can I die? It’s beyond my control.’ Then, they said: ‘Die’ and ‘You need to die.’ It’s so hard to hear that from others. (Cho et al. 2017)

Sometimes, such conflicts resulted in open violence:

> While I was sitting like now on the chair, she took off one of my slippers, and beat me with it on my face. She doesn't have morals or good manners. (Boggatz et al. 2009)

For some residents, a further source of annoyance was that sometimes roommates openly showed their gay or lesbian sexuality (Donaldson et al. 2014).

5.3.2.3 Attention to the Needs of Others

If residents refrained from exerting control it was not always a reaction to the experience of powerlessness. They also did so out of an attention to the needs of others which could be restricted if they put too high demands on them. Some residents had moved into a long-term care facility and agreed to stay there because they *feared to be a burden on the family* (Bradshaw et al. 2012; Chang 2013; Nakrem et al. 2013; Hillcoat-Nalletamby 2014; Cho et al. 2017; Rahayu et al. 2018). They wanted their children to have a happy and independent life, so they refrained from demanding to be cared for by them:

> My daughter said at the beginning, you come with us, and I said, Jane you and your husband and child, that's your life. And I said, you've got your life, I'll have my life I said. And I would never, never do that. I said no. All that matters to me is that my children are happy. And so I said, Jane I'm happy and quite happy with this. So that's good. (Hillcoat-Nalletamby 2014)

For the same reason, they did not expect family members to visit as often as they secretly wished (Park et al. 2012; Tompkins et al. 2012). At the same time, several residents *wanted to reduce burden on their caregivers* (Iwasiw et al. 1996; Bowers et al. 2001; Ball et al. 2004b; Hellström and Sarvimäki 2007a, b; Chuang and Abbey 2009; Nakrem et al. 2011, 2013; Behr et al. 2013, 2014; Oosterveld-Vlug et al. 2014; Roberts and Bowers 2015; Speller and Tollee 2015; Rekawati et al. 2018). Being aware of staff shortage and caregivers' work overload they tried to minimize unnecessary work for them, withheld from demands, did as much as they could for themselves, and avoided complaining as they did not wish them to get into trouble with their superiors.

> I try not to be unnecessarily calling on them all the time because they have enough to do as it is. (Ball et al. 2004b)

> Well to be honest, I would hate to get the girl in trouble by complaining so I do put up with things that I don't really agree with… I don't want the girl to lose her job or anything because I said something (Speller and Tollee 2015)

Some residents also made efforts to pay attention to their roommates needs. They tried to *show tolerance* even if they disliked their behaviour (Grau et al. 1995; Nakrem et al. 2013; Melin-Johansson 2014), and if any other measure failed they *avoided conversation to prevent conflicts* (Curle and Keller 2010; Christov 2016).

> They are not so easy to deal with, you know. It's the same with me, sometimes I just have to pull myself together and be a little more flexible if you know what I mean. (Nakrem et al. 2013)

5.3.2.4 Satisfaction of Attention to the Needs of Others

Several residents claimed that moving into a long-term care met their desire to pay attention to the needs of others because this *reduced the burden on their families*—a burden that was partly due to their worries about the fact that the older person had previously been living alone (Iwasiw et al. 1996; Walker and Curry 2007; Shin 2008; Cheng et al. 2011; Nakrem et al. 2013; Minney and Ranzijn 2016; Cho et al. 2017).

> They (family) come and visit and they are glad that I'm safe. They don't have to worry anymore. They worried when I was by myself and that something would happen to me (Minney and Ranzijn 2016)

If residents were unable to pay attention to the needs of others, they felt guilty. By moving into a long-term care facility, they could avoid such feelings with regard to their family. Regarding their relationship to staff members, however, there were care dependent residents who actually *felt to be a burden on their caregivers* (Ball et al. 2004b; Saunders and Heliker 2008: Falk et al. 2013; Hwang et al. 2013; Oosterveld-Vlug et al. 2014). They felt guilty and embarrassed by having to ask for help and if possible they tried to avoid it—even if their own needs remained unmet. The same was true for older women who felt unable to take care of her care dependent spouse. They *felt guilty for neglecting their marital duty*:

> I've got the guilt feeling all the time. […] I'd feel guilty if I wasn't looking after Edgar. But I do know that if I couldn't, I would be absolutely sensible and pay for whatever we could afford to have. (Shaw et al. 2016)

5.3.3 Social Adjustment Versus Unconventionality

Staying in a long-term care facility required an adjustment to social norms and expectations. Older persons were inclined to adjust since they wanted to avoid conflicts with caregivers and other residents. However, since social norms can be perceived as restrictive, residents also searched for opportunities to satisfy their need for unconventionality.

5.3.3.1 Social Adjustment

Residents had an often unspoken tendency towards social adjustment and conformity. They wanted to behave in a socially appropriate way and complied with social norms because they had been brought up that way. Disregarding social rules and standards seemed to be wrong to them. Conformity meant *adaptation to unwritten rules* (Iwasiw et al. 1996; Iwasiw et al. 2003; Chuang and Abbey 2009; Cheng 2013; Nakrem et al. 2013; Rekawati et al. 2018). It allowed to lead an orderly life and to feel normal.

> This is what you have to do – fit in – and be flexible. (Iwasiw et al. 1996)

> I go to bed at a normal time at night and get up at a normal time in the morning. One has to follow the routines in the nursing home, and that is just fine. Have no problems with that. (Nakrem et al. 2013)

One of these unwritten rules concerned the expression of one's own sexuality. Many older persons had grown up in a conservative climate in which sexuality was only acceptable among married heterosexual couples and if it served reproductive purposes. Therefore, any sexual relationship for mere pleasure, whether between people of the same sex or between people who had lost the ability to procreate, was morally unacceptable and those who were inclined to have such relationships tried to *hide their sexual desires and inclinations* (Nay 1992; Walker and Curry 2007; Frankowski and Clark 2009; Bauer et al. 2013; Donaldson et al. 2014; Villar et al. 2014)

> I and many like me, keep a check on behaviour… I know that those things [sexual expression] can't be done openly because they're not proper. I feel that the correct thing is to behave as if some impulses didn't exist. In my case, I've been influenced a bit by religion… sex is for procreation, you know, so, if there's nothing to procreate, then the right thing is to control yourself and retire. (Villar et al. 2014)

Conformity also meant to *be polite and well-mannered* (Ball et al. 2009; Chuang and Abbey 2009; Christov 2016; Heid et al. 2016). Residents made efforts to behave friendly and respectful and tended to avoid behaviours that others might consider inappropriate, such as gambling or drinking.

> They will think I'm an alcoholic if I say drinking is very important (Heid et al. 2016)

Some authors (Chuang and Abbey 2009) claim that politeness is a particular trait of Chinese culture with its tradition of collectivism where compromise for the sake of harmony is seen as a kind of virtue. According to them Chinese nursing home residents may be more cooperative, self-suppressive, and non-confrontational. However, findings from nursing homes in Western countries, which are said to have a more individualistic culture, suggest that at least some older persons there have similar tendencies towards conformity and social adjustment. Hence, differences between older persons from China and Western countries are more likely to be a matter of extent to which this trait is expressed.

An important aspect of social adjustment and conformity concerned the *observance of table manners* and appropriate behaviour with regard to elimination. These manners are the product of a particular culture and its members have been brought up to adhere to them. Non-adherence would make them feel ashamed of their behaviour (Sidenvall 1999). Residents therefore made an effort to eat decently and—if they were incontinent—not to bother roommates with the smell of their excrements (Nakrem et al. 2011).

5.3.3.2 Satisfaction of Social Adjustment

Residents, who were able to adjust to social norms and to behave accordingly, *felt normal and in tune with their social environment*.

> Being able to feed ourselves, without help, means we are normal. We don't need to be supervised in case we cause trouble or need help. (Palacios-Ceña et al. 2013)

In addition, adapting to rules gave some residents a *sense of structure and inner order* (Hjaltadóttir and Gustafsdóttir 2007; Cooney 2011; Philpin et al. 2011;

Palacios-Ceña et al. 2013; Gustavsson et al. 2015). For them, fixed schedules and routines were not a constraint but a guidance that prevented inner disintegration. The passage of time got clear contours that allowed orientation. Especially, mealtimes served as a compass.

> My schedule is determined by the meals…you have to organize yourself so that everything you do fits in between breakfast, lunch and dinner (Palacios-Ceña et al. 2013)

> I don't need a clock, when we are called for breakfast it is 9 o'clock, lunch is around one, and in the evening when the noise of carts is heard in the kitchen it's eight o'clock. (ibid.)

Residents, however, could not always meet their desire for conformity—even if such recognition was granted by others. If they were unable to adhere to social standards and good manners, it made them *feel ashamed*. Such feelings aroused when residents suffered from incontinence, needed help to use the toilet (Hweidi 1999; Koch-Straube 2003; Coughlan and Ward 2007; Behr et al. 2013; Perkins et al. 2013; Iden et al. 2015), had to be undressed in order to get personal care (Behr et al. 2013; Oosterveld-Vlug et al. 2014), or were unable to eat in a decent way (Sidenvall et al. 1994). All these situations had in common that they required skills that had been trained in early infancy. Their inabilities made the residents feel like a little child who could not assume the role of an adult person and behave in an appropriate way.

> I am often sad because I have to wear diapers and need help to use the bathroom. (Iden et al. 2015)

> You must undress…very unpleasant. And then you think 'Ok, now I'm even going to pull my underwear down in front of this person' (Oosterveld-Vlug et al. 2014)

> Now one is so old and crazy that one can't eat - now I need a bib… and they put it on if you ask, I'm afraid of spilling. I usually put a serviette on my knees because I take care of my clothes. I learnt that from my mother when I was a child. (Sidenvall et al. 1994)

Such failures to meet social standards made residents feel ashamed in front of their caregivers and prevented them from socializing with roommates because they considered themselves to be an unsuitable member of the community. As one resident in an assisted living facility who suffered from incontinence told:

> I don't have any [friends] because I'm very unattractive. I'm physically unattractive. (Perkins et al. 2013)

5.3.3.3 Unconventionality

Since adaptation to social norms can restrict spontaneity, a degree of unconventionality was needed to establish a healthy inner balance. Hence, there were also residents who told about their *reduced interest to conform to social standards* (Melin-Johansson et al. 2014). In men, this manifested as not shaving as often as they used to or not caring much about what clothes to wear. Grooming was not that important any more, and they showed a more relaxed attitude. But also some women became less concerned about their physical appearance.

> I am less particular about what clothes or hairstyle to wear, and whether the make-up is perfect. (Melin-Johansson et al. 2014)

Another resident explained that in old age it became less important to care about what people thought of one's behaviour. For example, one did not have to worry about the room being untidy or leaving the toilet door open, even if there were people around (ibid.).

Instead of just observing social norms residents wanted to be themselves and live out their peculiarities. For this reason, some of them had refused to stay with their children where they would have to adapt to their way of life. They *strove for their individual liberty* and the long-term care facility was perceived to be a place where they could find it (Boggatz et al. 2009; Chang 2013; Cho et al. 2017). During his own research in Egypt, the author met female residents who moved to a nursing home because they wanted to escape from restricting gender norms. In one case, the resident had been visually impaired all her life. This prevented her from marrying and she had to remain under the supervision of her family. An independent life for a woman living alone with a disability was hardly imaginable in Egyptian society and for her such a life became in part possible because her relatives finally brought her to a nursing home. In the other case, the resident had been married and raised her own children but after the death of her husband she did not want to stay with her son. She moved into a nursing home and openly rejected his expectation that according to the Egyptian tradition a mother had to be cared for by her son.

> I tricked him, I told him that I'm going to a friend and I had a small bag, so he drove me here. While he was coming in here… he told me that this is an older peoples' home. I said to him, yes and he got angry and asked me, did I make you upset? Is there anything that I'm not doing for you? I told him, no…and so, he cried and got really sad. He told me… that he cannot, when he wants to get married, tell his wife or her family that his mom is in an older peoples' home. This would mean that he is not a good boy. (Boggatz et al. 2009)

Such a perception of a long-term care facility was, however, only present if family life was perceived as restrictive. More often, life in the facility was experienced as restrictive since it required adjustment to rules and regulations the older persons were not used to. Not surprisingly, residents who were still able to do so *searched for a temporary escape*:

> I get the hell out of here … go down to the pub [in the facility] … talk to somebody. (Iwasiw et al. 2003)

In some cases, the desire for individual liberty could result in a *tendency to socially undesirable behaviour*. Instead of hiding their sexual desire some residents openly showed it by kissing or fondling each other in the public areas or by advocating the enjoyment of sexuality in old age (Nay 1992; Naess et al. 2016). Instead of adhering to decent manners, they consumed alcohol and even got drunk sometimes (Koch-Straube 2003; Slettebo et al. 2016). If residents felt that they could not do spontaneously what came into their mind because others reminded them to observe good manners, they sometimes showed an *aggressive self-assertion* as in the incident reported above by Fiveash (1998), in which one resident did not observe what others considered to be appropriate table manners and insulted her roommate by responding to a reprimand: “I’ll piss on the floor.”

5.3.3.4 Satisfaction of Unconventionality

For some residents, moving into a long-term care facility actually meant a *gain of an individual lifestyle*, as they did not have to adapt to their children’s way of life (Iwasiw et al. 1996; Boggatz et al. 2009; Bradshaw et al. 2012; Chang 2013; Cho et al. 2017).

> Here, I can do whatever I want to do, but if I stayed with my children, it would be awful [because they wouldn’t let me do things] (Cho et al. 2017)

> Since I’ve been here, I’ve begun to get my own self-esteem back. I love it. Now, I’m just beginning to live… I’m beginning to get my own world. (Iwasiw et al. 1996)

Other residents told about opportunities when they were *allowed to do what they liked*. One older man, for example, who attended ceramic classes, began to enjoy this work since “the guy down there [i.e. the occupational therapist] lets me do what I want” (Iwasiw et al. 2003).

Quite often, however, residents felt that they had to comply with social norms that existed in the facility. These norms made them feel that they *had to suppress their own needs* and prevented them from doing what they liked (Dobbs 2004; Falk et al. 2013; James et al. 2014; Palacios-Ceña et al. 2016b). Sometimes they were directly reprimanded by their roommates, but mainly they were just aware of their gossip and preferred to adapt to what they felt others perceived as social standards. Social standards concerned not only table manners or appropriate behaviour with regard to elimination but also the dress code. In assisted living facilities, where older persons had moved in to feel at home, residents felt urged to “dress up” because they were constantly on public display—although being at “home” would normally imply that one can dress however one chooses (Dobbs 2004). For example, when someone was sitting in the lobby in his pyjamas because he found it more relaxing, he was questioned by his roommates as to why he was ready for bed already. Conservative norms also prevented the wearing of outfits that were perceived as too erotic:

> I would like to show my cleavage or wear colourful clothes, but I prefer not to give them reasons to speak. Many people in the home can’t avoid gossiping about you and I don’t want my family to think badly of me. (Palacios-Ceña et al. 2016b)

Not surprisingly, such a climate constrained the free expression of one’s sexuality.

> Once, I commented what I liked with my friends, and they considered me to be a whore. I was only expressing what I liked or what I would have liked just out of curiosity. I never spoke [about it] again (ibid.)

5.3.4 Closeness Versus Distance

Social relationships of residents mainly depended on their desire for closeness and distance. The need to be cared for often implied a desire for closeness and social contacts which was also the reason why older persons adjusted to social norms and paid attention to the needs of others. Social distance on the other hand was facilitated by self-reliance and allowed for some non-conformity. Both tendencies, however, needed to be in balance in order to achieve social well-being.

5.3.4.1 Closeness

Even after moving into a long-term care facility, older people still felt the need for contact with the outside world and had a *desire for social participation* (Murphy et al. 2007; Cooney et al. 2009; Schenk et al. 2013; Behr et al. 2014; Teka and Adamek 2014). They wanted to feel connected to what was going on in the world outside, to stay up to date, and to get news about major events but also about their families and friends.

> So we keep in touch all the time, follow the government, see how they're going…if I couldn't keep in contact with the outside world, where would I be? (Cooney et al. 2009)

If possible, residents wanted to *maintain contacts to their friends outside* (Iwasiw et al. 1996; Murphy et al. 2007; Thomas et al. 2013; Walker and Paliadelis 2016; Shaw et al. 2016). Those who were still able to do so occasionally went out to visit them. The others depended on their friends to come to them. Most important for everybody was, however, the *desire for contact with the family* (Iwasiw et al. 1996, 2003; Bergland and Kirkevold 2006; Bland 2007; Hjaltadóttir and Gustafsdóttir 2007; Murphy et al. 2007; Stathi and Simey 2007; Harmer and Orrell 2008; Saunders and Heliker 2008; Cooney et al. 2009; Hutchinson et al. 2011; Nakrem et al. 2011; Park et al. 2012; Shrestha and Zarit 2012; Tompkins et al. 2012; Chang 2013; Hwang et al. 2013; Martinsson et al. 2013; Schenk et al. 2013; Thomas et al. 2013; James et al. 2014; Teka and Adamek 2014; Chuang et al. 2015; Gustavsson et al. 2015; Walker and Paliadelis 2016). Because of their lifelong relationship, residents were strongly attached to their children, who were therefore their main source of social well-being. They expected them to visit, to keep them up to date about what happened in the family, and to pick them up for outings

> I feel happy only if my family comes to see me. Otherwise, living here is very boring, and nothing is meaningful to me (Hwang et al. 2013)

The desire for closeness also referred to other residents. Many older persons were *interested in contacts with their roommates* (Ball et al. 2000; Grando et al. 2000; Rossen and Knafl 2003; Bergland and Kirkevold 2006; Robichaud et al. 2006; Andersson et al. 2007; Bland 2007; Stathi and Simey 2007; Wright et al. 2010; Nakrem et al. 2011; Andrews 2012; Kemp et al. 2012; Falk et al. 2013; Schenk et al. 2013; Thomas et al. 2013; Oosterveld-Vlug et al. 2014; Teka and Adamek 2014; Chuang et al. 2015; Bollig et al. 2016; Christov 2016; Minney and Ranzijn 2016;

Shaw et al. 2016; Rekawati et al. 2018). Some even had moved into a facility to find some company. They wanted to have someone to talk to who shared their joy and interests, and whom they could trust.

> When I signed up for this place I thought that I'd meet like-minded people and that we all could have a nice time together the last days or years of our lives. I hoped that it at least was someone here that I could make friends with, go for walks with, and talk about books with. (Falk et al. 2013)

> It is necessary to have friends here. (I) feel more cheerful, much happier and valued. (Chuang et al. 2015)

Residents made efforts to establish contacts and especially those who lived in single rooms searched for opportunities to meet other persons. Mealtimes were welcome as they provided such opportunities.

> I go down to dinners a lot. Talking to yourself all day long. So I'd rather go down to dinner. I just love going down with people, 'cos otherwise you're sat alone in this flat. (Wright et al. 2010)

Some residents wanted more than just occasional contacts in common rooms. They had an explicit *preference for close contacts* and did not mind an intrusion into their privacy (Thomas et al. 2013; Shin 2015). The company of roommates was rather welcome and the residents left their doors open for others to come in if they wished.

> They come in every night and visit me and we sit and watch the television from 6pm to 8.30 pm and we sit, the 3 of us together. We have supper in here also. It is so lovely having friends close by and at hand. (Thomas et al. 2013)

Some residents even had a *preference for shared rooms* which seemed to promote their sense of well-being and security (Fraher and Coffey 2011, Andrews 2012; Nakrem et al. 2013; Oosterveld-Vlug et al. 2013a). Surprisingly, this attitude was not restricted to traditional societies where people had a strong sense of community. It was also found in Western countries where people are said to be rather distanced and individualistic.

> At home I also slept on my own since my husband died 14 years ago. In here I share with four others, but they are all very nice. They all welcomed me, and we are all good to each other. (Fraher and Coffey 2011)

For some older men the desire for closeness was related to *searching for a female partner*. They had even moved into a long-term care facilities in the hope of finding someone suitable (Iwasiw et al. 2003; Boggatz et al. 2009).

The desire for closeness, however, did not extend to every roommate. Rather, the residents made *contacts according to their inclination*. This inclination was sometimes determined by feelings of sympathy.

> When you first meet people, you can kind of tell if that's the kind of person you want to build a friendship with. And then as it progresses and you find you have more and more things in common, it grows and grows. (Kemp et al. 2012)

Shared interests around music, sports, gardening, books, art, travel, and even pornography provided another foundation for relationships (Kemp et al. 2012; Park et al. 2012, 2013).

> I specifically like to select people that talk about things that I have an interest in. Because sometimes the conversation is not interesting. It's not about things that you have an interest in. (Park et al. 2013)

Quite often, however, the background for sympathy and shared interests was commonality based on race, class, gender, functional ability, culture, regional ties, religion, and even age (Kemp et al. 2012; Park et al. 2013; Perkins et al. 2012, 2013). As one resident put it:

> There's nothing like being with your own [race]. (Perkins et al. 2012)

Although relationships based on such commonalities are an understandable trait of human behaviour, they also implied the rejection of other persons considered unsuitable to fit into a particular community. A 92-year-old resident, for example, explained why he did not include some roommates in his network:

> They are all old, over 90, a bunch of old people. (Perkins et al. 2013)

Such rejection could also concern prospective residents who came to have a look on the facility. A manager who showed such an older person around told how she was approached by one of the residents who informed her: "We have already decided, she's not a candidate" (Kuhn 2008). Especially residents in assisted living facilities tried to exert some influence on the admission of new persons in order to maintain a social climate that corresponded to their lifestyle. Providers were aware of these preferences and made efforts to select residents who fitted well with the culture of their homes, but because they had to avoid vacancies all facilities also included residents viewed by the larger collective as outsiders, misfits, or troublemakers (Perkins et al. 2012).

More than any other contact, however, contacts with caregivers were of particular importance and residents expressed their *desire for a positive relationship to staff* (Bowers et al. 2001; Josat 2005; Bland 2007; Bergland and Kirkevold 2006; Coughlan and Ward 2007; Westin and Danielson 2007; Harmer and Orrell 2008; Hauge and Heggen 2008; Cooney 2011; Nakrem et al. 2011, 2013; Chang 2013; James et al. 2014; Teka and Adamek 2014; Gustavsson et al. 2015; Bollig et al. 2016; Lung and Liu 2016; Walker and Paliadelis 2016). Caregivers were perceived to be a central source of their well-being. They were those they could talk to even if they had no more contacts to roommates, family, or friends. Hence, they wanted to obtain their empathy and in return they took part in their private affairs.

> I treat the nursing assistants like my friends, which means that we share what has happened here and comfort each other. (Lung and Liu 2016)

5.3.4.2 Satisfaction of Closeness

Residents in long-term care facilities could satisfy their desire for closeness to various degrees. They had several ways to attain *social participation*. For some of them reading, listening to the radio, or watching TV was sufficient to feel connected to the world outside (Thomas et al. 2013). Others, who were still mobile, participated in activities arranged by the community, such as meetings for seniors (Falk et al. 2013). Those who were less able to leave the facility were satisfied with sitting inside and watching people on the street or at a nearby supermarket through a window as it gave them the feeling of taking part in other persons' lives (Bollig et al. 2016). Observing what was going on in the entrance hall or in a café inside the facility had the same effect and provided some entertainment (Andrew and Wilson 2014). Others, however, complained about a *loss of social participation* (Oosterveld-Vlug et al. 2014; Canham et al. 2016). Staying inside a facility meant for them that they were no longer part of the society. They felt far away from their community, lacked social ties, and had a sense of being abandoned.

A sense of social participation was reinforced if residents *succeeded in maintaining old contacts*. Some received visits from friends outside (Ball et al. 2000; Al-Omari et al. 2005; Kennedy et al. 2005; Park et al. 2012; Koppitz et al. 2017), stayed in contact via telephone and sometimes the internet (Williams and Warren 2008; Svidén et al. 2009; Minney and Ranzijn 2016), or went outside to meet them (Park et al. 2009; Svidén et al. 2009; Martinsson et al. 2013; Shaw et al. 2016).

> When they [outside visitors]'re here, we have very good visits. Quality time. We just chat for an hour … when he comes in at nine-thirty, I know at ten-thirty he'll be leaving. And the other one comes in and he just stays an undetermined length of time. And we just talk. I don't know much to talk about, but we pass quality time for an hour or so. (Park et al. 2012)

Although such contacts were more frequently reported in assisted living facilities, they were also found to some extent in nursing homes. More often, however, residents reported about a *loss of old contacts* (Ball et al. 2000; Rossen and Knafl 2003; Dobbs 2004; Shippee 2009; Svidén et al. 2009; Cheng et al. 2011; Chang 2013; Oosterveld-Vlug et al. 2013a, 2014; Thomas et al. 2013; Martinsson et al. 2013; James et al. 2014; Bennett et al. 2015; Canham et al. 2016; Koppitz et al. 2017). They were yearning for old times they had spent with their friends. All that remained now was some memories. Their friends had died or were sick and unable to visit them and they felt lost and abandoned.

> We used to get together often and have some meals with a little humble vegetable dish. I used to live like that, but now I feel like I live in exile (Chang 2013)

> We have called each other in the last years because we do not meet. As it was, she was gone when she could not talk on the phone anymore, but she is still alive — 101 years she is — but we are losing each other. (James et al. 2014)

In this situation contacts to the family became even more important and the desire for closeness was satisfied if residents had a *positive relationship to their family*

(Iwasiw et al. 1996; Murphy et al. 2007; Tsai and Tsai 2008; Wu et al. 2009; Nakrem et al. 2011; Tompkins et al. 2012; Hwang et al. 2013; Martinsson et al. 2013; Thomas et al. 2013; O'Shea et al. 2014; Oosterveld-Vlug et al. 2014; Adra et al. 2015; Bennett et al. 2015; Gustavsson et al. 2015; Bollig et al. 2016; Minney and Ranzijn 2016; Tuominen et al. 2016). Beside the already mentioned practical support and feeling of being cared for, visits from their children provided the opportunity to talk with a close person and to have someone who listened and showed his empathy.

> My son is a very filial child. He comes to visit me every day. He also brings food for me such as fruit or cookies. He says, 'Mom, all you have to do here is to nurture your health. You don't have to think too much' (Tsai and Tsai 2008)

Others, however, complained about *limited or even no contact to their family* (Ball et al. 2000; Saunders and Heliker 2008; Boggatz et al. 2009; Chuang and Abbey 2009; Timonen and O'Dwyer 2009; Cheng et al. 2011; Tompkins et al. 2012; Chang 2013; Schenk et al. 2013; Thomas et al. 2013; Bennett et al. 2015; Gustavsson et al. 2015; Mohammadinia et al. 2017). Their children lived far away, were too busy to visit them regularly, or had broken off their relationship with their parents. In some cases, they were non-existent.

> When I moved into here it has become too hard to see them because none of them can drive to come and see me because it's too hard. (Thomas et al. 2013)

> Since I have been here, nobody has visited me, even my children do not reply to my phone calls. Nobody understands me here; there is neither sympathy nor talking. (Mohammadinia et al. 2017)

This experience was aggravated when they had to witness how their roommates received love and attention from their children.

> When I see them celebrating their birthdays, and in come the relatives, sisters, brothers, and all the aunts and uncles, and yet I have nobody. I have nobody, not a single person. (Schenk et al. 2013)

There were also some residents who had been *separated from their spouse* when they had to move into a nursing home (Coughlan and Ward 2007; Iden et al. 2015).

> We have been married for ages. Moving into nursing home was like getting a divorce. It was very sad, even though she visits me every day. (Iden et al. 2015)

Others were in an even worse situation because they suffered from *grief due to the loss of significant others* (Coughlan and Ward 2007; Nakrem et al. 2011; Martinsson et al. 2013; Melin-Johansson et al. 2014; Teka and Adamek 2014; Kemp et al. 2016). One older women told, how she experienced the loss of her son:

> I discussed everything with him; he was nearby to me at any situation. He used to visit me frequently. Unfortunately, he died 7 years back; starting from those days for me life is meaningless; no happiness; I feel severe headache. When I am thinking about him I do not want to talk with anyone. (Teka and Adamek 2014)

In contrast to these residents, there were occasionally *couples who enjoyed their company* after they had moved in together. Their close relationship made them less dependent on contact with their roommates and they felt sorry for those who were in a less fortunate situation:

> We have companionship that they don't have. It's very, very difficult for most of the people here because […] they've lost their spouse. (Kemp 2008)

In some cases, residents also found *new partnerships* that satisfied their desire for closeness.

> I just fell in love with that man. You know, I didn't even love my husband like I love him. (Kemp et al. 2016)

Such relationships did not necessarily involve sexuality, but like their married counterparts, unmarried couples spent most of their time together although they did not share a room. In nursing homes with a lack of privacy romantic relationships could be restricted to showing love and affection by holding hands or taking care of one another. Whereas such relationships were tolerated to some extent in Western countries, *contacts between the sexes were rather restricted* in cultures where gender segregation was a predominant value. Hweidi (1999), for example, reported about a Jordanian nursing home that social interaction between male and female residents seemed to be non-existent except for some meetings which occurred at the entrance or in the club hall when both genders happened to be there at the same time. But also long-term care facilities in Western countries did not always offer the possibility to find new partners and those who had moved in in search of someone remained sometimes unsatisfied and began to complain about loneliness or as one of them summarized his experience: “There is no love here” (Iwasiw et al. 2003).

Besides families, old friends, or new partnerships, roommates were of particular importance in meeting the desire for closeness. Quite often residents reported about *positive relationships with their roommates* (Iwasiw et al. 2003; Cooney et al. 2009; Curle and Keller 2010; Cooney 2011; Bradshaw et al. 2012; Thomas et al. 2013; Andrew and Wilson 2014; Hillcoat-Nalletamby 2014; James et al. 2014; Lung and Liu 2016; Koppitz et al. 2017; Rahayu et al. 2018). Spending their time together and knowing that there was always someone available to talk to saved them from feelings of loneliness.

> I can just make a short walk to the dining room and there are always people sitting around in the dining room. I just go and talk to them (Thomas et al. 2013)

> There's no feeling of loneliness about it, you know it's a companionable place. (Cooney 2011)

Some facilities apparently managed to establish a positive social climate as researchers could observe how residents mutually expressed their friendship and appreciation (Curle and Keller 2010). In such places, residents told how they developed a *sense of community* and a feeling of belonging to the facility (Saunders and Heliker 2008; Eckert et al. 2009; Cooney 2011; Kemp et al. 2012). As one of them put it: others became “just like family” (Kemp et al. 2012)

> We have a good rapport with each other … it's not like your own family but you make them your family. (Cooney 2011)

For some residents, their *new contacts in the facility became a substitute* for old but lost relationships to families and friends (Westin and Danielson 2007; Bennett et al. 2015; Canham et al. 2016).

> Yes, it means almost everything, when you do not have any relatives, but you feel that in some way you belong here in this home, that you are one among the others and you always have someone to turn to. (Westin and Danielson 2007)

For others, moving into the facility even meant a *gain of contact* because they were widowed or childless and had less opportunity to socialize when they were still living at home (Iwasiw et al. 1996; Saunders and Heliker 2008; Bowers et al. 2009; Cheng et al. 2011; Falk et al. 2013; Nakrem et al. 2013; Oosterveld-Vlug 2013a; Schenk et al. 2013; Oosterveld-Vlug et al. 2014; Teka and Adamek 2014; Adra et al. 2015; Minney and Ranzijn 2016).

> I didn't socialize much, only with my husband [who died], but I knew if I came here I would need to change and I did and it's been good. (Bowers et al. 2009)

Social interaction mainly occurred in public areas of the facility. Residents regularly met at meals, which for this reason meant more than just the intake of food and calories (Sidenvall et al. 1994; Iwasiw et al. 1996; Wu and Barker 2008; Curle and Keller 2010; Hweidi 1999; Philpin et al. 2011; Barnes et al. 2013; Thomas et al. 2013; James et al. 2014; Gustavsson et al. 2015; Canham et al. 2016; Slettebo et al. 2016). Sharing food allowed for conversation and created bonds between residents as they became familiar with each other.

> Nice fellows, we sit there at the table joking and teasing each other, children of the same spirit as I am. (Sidenvall et al. 1994)

Another occasion to socialize was participation in joint activities organized by the staff (Iwasiw et al. 1996; Raske 2010; Pryce and Gooberman-Hill 2012; Oosterveld-Vlug 2013a; Schenk et al. 2013; James et al. 2014; Adra et al. 2015; Gustavsson et al. 2015). Besides these arranged possibilities, contacts were made in the common room (Koch-Straube 2003; Hubbard et al. 2003; Nakrem et al. 2011; Thomas et al. 2013; Christov 2016) or—if available in the facility—in the café (Andrew and Wilson 2014) or while waiting for the hairdresser (Thomas et al. 2013).

Such contacts, however, did not result for every resident in the formation of close ties with other roommates. There were also those who *experienced their relationships as friendly but superficial,* because their contacts remained restricted to occasional conversation in public areas (Ball et al. 2000; Koch-Straube 2003; Dobbs 2004; Hutchinson et al. 2011; Kemp et al. 2012; Park et al. 2012; Bennett et al. 2015; Roberts and Bowers 2015).

> I have acquaintances here, but don't get too involved. (Kemp et al. 2012)

> I mean they're all friends [but] I don't confide in them, you know what I mean. We're all separate. It's not like when you're younger. (Park et al. 2012)

For these residents, relationships labelled as friendships were rather "artificial" as they did not develop out of mutual understanding but occurred "simply because they live in the same place" (Park et al. 2012). Some residents, however, would not generalize such statements. They rather developed *individual friendships* with some roommates when there was mutual sympathy (Ball et al. 2000; Coughlan and Ward 2007; Tucket 2007; Kuhn 2008; Williams and Warren 2008; Svidén et al. 2009; Kemp et al. 2012; Park et al. 2012; Falk et al. 2013; Andrew and Wilson 2014; Gustavsson et al. 2015; Roberts and Bowers 2015; Bollig et al. 2016)

> I have a friend that's a real good friend of mine. When I came in the door, she said, 'That's gonna be my friend.' Me and her turned out to be best friends that ever was. We still are. (Ball et al. 2000)

However, close contact did not always mean familiarity. For some, it was just acceptable and better than loneliness.

> I've got two women here, (Margaret) and another one (Joan), I don't know her surname … they come into my room invariably, sit and talk to me… They're patients – inmates… They're not good friends or anything like that. I realize I can talk to them. We lend each other books and things like that. (Tucket 2007)

Quite often, however, residents felt that there was no suitable person available to establish closer contacts or friendship and they suffered from a *lack of contacts with roommates* (Sidenvall et al. 1994; Fiveash 1998; Andersson et al. 2007; Hjaltadóttir and Gustafsdóttir 2007; Tucket 2007; Hauge and Heggen 2008; Tsai and Tsai 2008; Wu and Barker 2008; Bowers et al. 2009; Chuang and Abbey 2009; Cooney et al. 2009; Timonen and O'Dwyer 2009; Cooney 2011; Philpin et al. 2011; Nakrem et al. 2011; Andrews 2012; Bradshaw et al. 2012; Pryce and Gooberman-Hill 2012; Barnes et al. 2013; Chang 2013; Falk et al. 2013; Martinsson et al. 2013; Nakrem et al. 2013; Schenk et al. 2013; Thomas et al. 2013; James et al. 2014; Melin-Johansson et al. 2014; Oosterveld-Vlug et al. 2014; Iden et al. 2015; Roberts and Bowers 2015; Shin 2015; Stevens et al. 2015; Bollig et al. 2016; Christov 2016; Tuominen et al. 2016; Slettebo et al. 2016; Cho et al. 2017; Mohammadinia et al. 2017). This was reported to some extent from assisted living facilities, but it was a more common complaint in nursing homes where residents had higher levels of care dependency. Some older persons felt that their roommates did not share their interests or that they had a different social background. Others felt restricted by a cold social climate.

> I just didn't get on with the people there. It was – you know, it was like a wall. Yes. There was just no, no connection among the residents, and so I said to myself, the first opportunity I get, I'm getting out of here. (Schenk 2013)

> I do nothing. I sit in the living room in my own stress-less chair. I have tried to involve other residents in a conversation but I get no response, so I have stopped doing that. (Slettebo et al. 2016)

Because the majority of residents were women, men sometimes felt restricted by the dominance of female topics and interests.

> At the dinner table, there's 10 people *(women) and* one man… With a woman, you know, sewing and cooking and that don't interest me. (Bauer et al. 2013)

The most common complaint, however, was that roommates were unable to communicate due to dementia or hearing impairments.

> There are no normal people here. Almost every person has dementia or is wheelchair-bound… it's hard to communicate with them (Cho et al. 2017)

> It's so sad that I can't talk to any of the others. They're all in a world of their own – old and silly. (Hauge and Heggen 2008)

There were also residents who had been lucky enough to find some friends when they had moved in, but they eventually experienced a *decline of their social contacts* because roommates that had become their friends left or died (Park et al. 2009; Bennett et al. 2015).

Others lost social contacts due to declining cognitive abilities and being in the initial stage of dementia they were aware of this loss.

> There's probably half a dozen people who've come within the last few months that I've never met and some of them, if I get close enough, are peering at me and they're 'why doesn't he say anything?' You can see their thoughts on their faces. Because they expect the men to introduce themselves first, don't they. (Shaw et al. 2016)

Due to their work, staff members were the most important source of social contacts for the residents. Quite often, residents told about the *attention and friendliness of staff*, which met their desire for closeness (Iwasiw et al. 1996; Iwasiw et al. 2003; Bland 2007; Cho et al. 2017; Murphy et al. 2007; Westin and Danielson 2007; Tsai and Tsai 2008; Svidén et al. 2009; Williams and Warren 2009; Wu et al. 2009; Jordan 2010; Hutchinson et al. 2011; Nakrem et al. 2011; Hwang et al. 2013; Park et al. 2013; James et al. 2014; Oosterveld-Vlug et al. 2014; Gustavsson et al. 2015; Rekawati et al. 2018). They described caregivers as kind, pleasant, and helpful, and they recounted how they took their time, listened to them, showed their compassion, and did small favours to them.

> The nurses listen to whatever I say, and we laugh together (Cho et al. 2017)

> The staff are wonderful, I can talk about anything I like … the girls are exceptional, always helpful and in a good mood. Not even in my dreams could I have expected it would turn out so well. (Svidén et al. 2009)

Not surprisingly, many older persons told that they developed *close relationships to their caregivers* that made them feel loved and less lonely (Grant et al.1996, B78; Ball et al. 2000, 2004a, 2009; Al-Omari et al. 2005; Bland 2007; Coughlan and Ward 2007; Westin and Danielson 2007; Eckert et al. 2009; Jordan 2010; Cooney 2011; Nakrem et al. 2011; Philpin et al. 2011; Park et al. 2012; Adra et al. 2015;

Shin 2015; Stevens et al. 2015; Canham et al. 2016). For many of them, caregivers became like friends or even family members and some of them welcomed being called grandma or grandpa by the staff.

> I know that I am comfortable in here and that the employees are so sweet. They love me and they treat me as if I were their mother or grandmother. (Adra et al. 2015)

> So caring is treating me as a family such as by calling me grandma, holding or touching me, greeting me actively every day, and accompanying me for a while. (Hwang et al. 2013)

For residents who had only limited contacts to family, friends, or roommates, *contact to caregivers became a substitute* for their lack of relationships, and they were to some extent dependent on their attention (Hauge and Heggen 2008; Park et al. 2009, 2013; Hwang et al. 2013; Mohammadinia et al. 2017).

> Here, older people rarely talk to each other or walk outside. I like having staff inquiring about me… (Hwang et al. 2013)

Not every resident, however, experienced a close relationship to caregivers. There were also those who described their *contact to staff as friendly but superficial*—at least when certain caregivers were concerned (Heliker and Scholler-Jaquish 2006; Jordan 2010; Nakrem et al. 2013; James et al. 2014; Iden et al. 2015; Donnelly and MacEntee 2016; Lung and Liu 2016). According to these residents there was nothing "wrong" with such staff members, but they lacked the affection that had been shown by others (James et al. 2014). According to Lung and Liu (2016), who investigated nursing homes in Hong Kong, such polite but formal relationships helped avoiding conflict and maintaining a harmonious atmosphere that is valued in Chinese culture. Although this type of relationship may be particularly pronounced in Chinese facilities, a friendly tone, which lacks authenticity, is by no means unknown in other countries, as it is shown by the following quote:

> They're too pleasant. (laughter), They come in here with a big smile on their face but I don't know how they leave when they turnaround. They're always nice to you, you know. But, you never know if they really mean it. I mean that's just my feeling. (Jordan 2010)

Others did not report about a lack of authenticity in their relationship to caregivers. They rather told that they had only *limited contact to staff* (Dobbs 2004; Heliker and Scholler-Jaquish. 2006; Martinsson et al. 2013; Gustavsson et al. 2015; Bollig et al. 2016). Caregivers were perceived to be distanced or too busy to spend time with residents. In some facilities, residents rarely knew the names of the staff even after 3 months (Heliker and Scholler-Jaquish. 2006).

> I miss the contact. They do not have time (Gustavsson et al. 2015)

Furthermore, older persons who were immigrants reported a language barrier that prevented them from establishing closer relationships to staff:

> It would be nice if someone here could speak my language so I can feel secure … There is one person on the staff who can speak my language, but when she is not here, I do not want to talk. (Martinsson et al. 2013)

If residents lost contact to family and friends outside and felt that they could not establish new contacts to roommates and caregivers inside the facility, they eventually suffered from *loneliness* (Iwasiw et al. 1996; Fiveash 1998; Ball et al. 2000, 2004a; Coughlan and Ward 2007; Westin and Danielson 2007; Saunders and Heliker 2008; Tsai and Tsai 2008; Warren and Williams 2008; Chuang and Abbey 2009; Shippee 2009; Timonen and O'Dwyer 2009; Cheng et al. 2011; Cooney 2011; Hweidi 1999; Kemp et al. 2012; Tompkins et al. 2012; Chang 2013; Martinsson et al. 2013; Schenk et al. 2013; Behr et al. 2014; Hillcoat-Nalletamby 2014; James et al. 2014; Melin-Johansson et al. 2014; Oosterveld-Vlug et al. 2014; Teka and Adamek 2014; Adra et al. 2015; Chuang et al. 2015; Nakrem 2015; Walker and Paliadelis 2016; Cho et al. 2017). This experience was not restricted to nursing homes where residents suffered from disabilities that prevented them from developing relationships. Loneliness was also found in assisted living facilities, where social contacts seemed to be better. Some residents were just excluded from the social networks in the facility and they became outsiders.

> I don't know where I am, I'm isolated. This isn't the place for me I'm so lonely (Hillcoat-Nalletamby 2014)

> I can't communicate with the people here. There's nobody to talk to at all. I feel absolutely terrible, don't I? I have no one to talk to! I want a friend… I like talking. I'm dying to have a friend to talk to. (Chang 2013)

To some extent, loneliness seemed to be the reason for unusual behaviours that could be observed among residents. For those who could not describe their feelings, crying out for help for no obvious purpose was the only way to attract some attention (Ball et al. 2004a).

5.3.4.3 Distance

The desire for closeness, however, was counterbalanced by a desire for distance. First of all, distance was ensured by *maintaining privacy*. Privacy meant to have one's own space that was surrounded by a personal boundary. The extent of personal space, however, could vary. Whereas many older persons wanted to have a single room (Hjaltadóttir and Gustafsdóttir 2007; Hauge and Heggen 2008; Chin and Quine 2012; Nakrem et al. 2013) and expected caregivers to knock before entering (Oakes and Sheehan 2012; Chuang et al. 2015; Bollig et al. 2016), others did not mind shared rooms due to their desire for closeness. They nevertheless insisted on a private sphere as they had their own area in a shared room that others were not allowed to step in without permission (Murphy et al. 2007). Gubrium (1997) observed how privacy was enacted in public areas, for example, by claiming an exclusive right to use a certain place. Such rights were tacitly acknowledged by other roommates in order to avoid conflicts. Some residents also wanted to have their privacy to perform their own activities without being disturbed by others. Iwasiw et al. (2003), for example, observed a resident who filled his day by playing the piano and avoided in this way the interaction with others. As he said, "I'm busy with…music.… You just block yourself right off from what's around you" (ibid.).

Maintaining privacy was associated with a *desire for temporary withdrawal* (Harmer and Orrell 2008; Hauge and Heggen 2008; Nakrem et al. 2011; Melin-Johansson et al. 2014; Stevens et al. 2015; Christov 2016). Residents wanted to balance their need for company and their need to be alone by choosing how much time they spent in the common room and in their private space.

There were also residents who had just a *restricted desire for contacts with other residents* due to a variety of reasons. Some had reservations about their roommates and since they believed that they still had enough contacts to friends outside they felt no need to establish closer contacts inside (Perkins et al. 2013; Shaw et al. 2016)

> I don't want to get tied into anyone here, particularly because living here with them if they're not my cup of tea […] So I'm very much making a conscious decision that I will be friendly with everyone but not to sort of forge a great relationship because I'm in the position that I don't feel lonely that I've got a good circle of friends that I don't need to look for another friendship really. (Shaw et al. 2016)

In nursing homes such reservations about roommates were due to their impairments or dementia (Oosterveld-Vlug et al. 2014). This made even those who felt a need for closeness less inclined to search for new contacts. For men, lack of shared interests with predominantly female roommates was a reason to remain distant (Park et al. 2009; Williams and Warren 2009). For others, dislike of gossip as it occurred in long-term care facilities was a reason not to get too involved in their social networks (Perkins et al. 2013; Roberts and Bowers 2015; Kemp et al. 2016).

> Well, a lot of times it's gossip. And I don't like that. Not very much. I like to know what's going on but I don't like to, I don't like the gossip part of it. (Roberts and Bowers 2015)

Others perceived themselves to be loners by nature and were satisfied when they were left alone and could pursue their individual activities and interests (Ball et al. 2000; Eckert et al. 2009; Williams and Warren 2009; Kemp et al. 2012; Martinsson et al. 2013; Roberts and Bowers 2015; Stevens et al. 2015).

> I have never been fond of socializing so I am used to taking care of myself and entertaining myself. I can always pass the time reading, watching television and listening to the radio, solving crosswords and so on. So I am pretty much alone. In a way, I don't care for the entertainment they offer here. (Slettebo et al. 2016)

Shyness and feelings of shame (for example, due to incontinence) were other motives for social distance (Iwasiw et al. 1996; Rossen and Knafl 2003; Jordan 2010; Cheng et al. 2011). Some residents, finally, avoided close contacts because they had been hurt by the loss of friends and were afraid of having to repeat this experience.

> Yeah, I don't want [friends] anymore. I don't want to see the friend die. Or, eat supper and be dead by breakfast time. (Park et al. 2009)

There were also residents who wanted to have a *distanced relationship to caregivers* (Andersson et al. 2007; Nakrem et al. 2011; Lung and Liu 2016). They felt that they were too young to understand older persons and had interests they could not share. Because caregivers were no real substitute for family and friends, residents preferred that they just fulfilled their function without establishing any closer relationship with them.

> There is not much chatting between the nursing assistants and me because, as a resident here, and the nursing assistants are the workers, so we lead different lives…. There is nothing to talk about … I mean, we do not interact like friends; there is not much joking, or chatting…. These things are all on me, and are none of their business […]. We, residents are those who need to be taken care of… they are care workers…. Our relationships can't go beyond this…. I mean, there is no way for us to be friends at all. (Lung and Liu 2016)

There were also residents who were *inclined to complete disengagement* (Koch-Straube 2003; Shippee 2009; Williams and Warren 2009; Curle and Keller 2010; Pryce and Gooberman-Hill 2012; Christov 2016). Being forced to move into a long-term care facility and dissatisfied from life they withdrew out of inner protest.

> I just made up my mind that things had to change, so I just erased from my mind these other relationships. (Shippee 2009)

For them, the facility and their roommates were a permanent annoyance. If they could not avoid their presence because they suffered from impaired mobility and had been taken out of their rooms by caregivers, they preferred not to communicate with others. Their silence created a barrier that protected what was left of their privacy.

5.3.4.4 Satisfaction of Distance

The desire for distance was satisfied when residents had a single room or apartment that *protected privacy* (Murphy et al. 2007; Cooney et al. 2009; Bauer et al. 2013; Falk et al. 2013; Nakrem et al. 2013; Hillcoat-Nalletamby 2014; Shin 2015). This demand was particularly met in extra care housing and assisted living facilities which had been established for this purpose, but also nursing homes fulfilled this requirement if residents had single rooms and caregivers respected their privacy.

> You have a carer coming in the same, but here you've got a little bit more privacy, you've got your bedroom, you've got your bathroom, you've got your kitchen, you can have your visitors in. (Hillcoat-Nalletamby 2014)

Privacy, however, was fragile and some residents complained about an *intrusion of privacy by caregivers* (Nakrem et al. 2011; Chuang and Abbey 2009; Oakes and Sheehan 2012; Falk et al. 2013; Schenk et al. 2013; Chuang et al. 2015; Nakrem 2015). They felt disturbed when caregivers entered their room without knocking on the door and they disliked monitoring, especially night checks, which staff performed in the interest of their health and safety. If residents, however, were care dependent, an intrusion of their privacy was unavoidable as caregivers had to provide personal care. Another source of annoyance was the *disturbance of their privacy by roommates* who entered unannounced their room and sometimes even took away their private possessions (Bradshaw et al. 2012; Behr et al. 2013; Koskenniemi et al. 2015).

> When I want to be alone, some residents always come to my room… and I have to drive them away. It is horrible…I want to be alone - there is so much noise in the living room. (Koskenniemi et al. 2015)

Lack of privacy also meant that there was no or only limited place for private belongings due to risk of theft (Timonen and O'Dwyer 2009; Cooney et al. 2009; Cooney 2011). Furthermore, it restricted the opportunities for social contacts according to residents' desires. Due to the constant presence of roommates, there was no place where residents could retreat to meet with others for private reasons. It also made visitors feel unwelcome as everybody could observe their private encounter (Timonen and O'Dwyer 2009; Cooney et al. 2009; Fraher and Coffey 2011; Nakrem et al. 2011, 2013).

> In the day room there's a certain lady and she listens to every word that those people… I think it's very wrong. It's very embarrassing for the visitors to have someone listening. (Timonen and O'Dwyer 2009)

As mentioned above, the lack of private space also restricted the satisfaction of sexual desires (Bauer et al. 2013; Villar et al. 2014).

5.3.5 Influencing Factors

The balanced satisfaction of social needs depended on the one hand on the residents' physical condition and their circumstances of life. On the other hand, it was influenced by environmental factors and the way how caregivers dealt with their social needs. In response, residents showed a variety of coping reactions.

5.3.5.1 Physical Conditions

Functional limitations prevented residents from participation in joint activities (Andersson et al. 2007; Nakrem et al. 2011; Chang 2013; Thomas et al. 2013; Gustavsson et al. 2015; Cho et al. 2017):

> When I hear and see others laugh and enjoy [themselves], I desperately want to join them … but now it takes a lot longer than before for me to walk … anywhere, so it's hard for me to join others… I'm very disappointed. (Cho et al. 2017)

Those who were wheelchair-bound depended on their caregivers to get in touch with others and to return to their privacy. *Loss of hearing* was a serious obstacle to establish communication (Hubbard et al. 2003; Andersson et al. 2007; Chuang and

Abbey 2009; Curle and Keller 2010; Philpin et al. 2011; Pryce and Gooberman-Hill 2012; Melin-Johansson et al. 2014; Gustavsson et al. 2015; Stevens et al. 2015). Residents could not understand what the others said and were afraid to annoy them because those who spoke complained about having to repeat what they had already told them:

> My hearing is so difficult and a number of the people here have hearing and speech difficulties and I haven't been able to sort out those who are speaking clearly and those who don't. I don't want to embarrass them or me. (Stevens et al. 2015)

Cognitive decline was another obstacle for social contacts (Ball et al. 2004a; Curle and Keller 2010; Nakrem et al. 2011; Andrews 2012; Sandhu et al. 2013; Chang 2013; Schenk et al. 2013; Behr et al. 2014; Oosterveld-Vlug et al. 2014; Cho et al. 2017). Those who suffered from it either could not understand what others were talking about or they deterred them with disruptive behaviour.

> We have a lot here, (…) who go crazy sometimes, don't they? (…) if you now talk to the lady and say, we go to the room (…) no, she doesn't (…) then sometimes they get really angry (…) because she insults them with crazy words (…) Because she beats her – gives her a blow. Well, that can't be true, is it? (….) the next day they are quite fine and normal again? (Behr et al. 2014)

At the same time, cognitive integrity was a prerequisite for remaining independent and self-reliant.

> If you don't have Alzheimer's yet or Parkinson's and the confusion isn't there, then you can still decide for yourself where to get out and where to go.(Schenk et al. 2013)

Residents were afraid of getting dementia, and they saw it as a disease that could strike them without their being able to do anything about it.

5.3.5.2 Circumstances of Life

The satisfaction of social needs was furthermore affected by the life circumstances of the residents. There were those who had *moved in by own choice* (Iwasiw et al. 1996; Rossen and Knafl 2003; Andersson et al. 2007; Walker and Curry 2007; Cooney et al. 2009; Svidén et al. 2009; Cooney 2011; Nakrem et al. 2013; Stevens et al. 2015). This allowed them to maintain control over their life as they were able to anticipate and prepare for the move. Since the long-term care facility was only possible option for them, they also could realize some advantages of moving in. One advantage was the feeling of being cared for.

> After my wife died, I was alone out on the island and that just wouldn't work. Got this here thing with my foot and I just couldn't be out there alone on the island, under any circumstances, without home healthcare. (Nakrem et al. 2013)

The opportunity to establish new contacts was another advantage and they were ready for some social engagement. Consequently, they entered the "home" with a mind-set of "giving it a go" or "making it work" (Cooney 2011). In some cases, their decision had been influenced by family members, but since these only gave them advice but did not impose anything on them, they finally considered the decision to be their own (Stevens et al. 2015).

Financial resources increased resident's possibilities of choice and thus their amount of control (Ball et al. 2004a; Bowers et al. 2009; Eckert et al. 2009). They were particularly important when moving into assisted living, as accommodation there usually had to be paid for privately. Older persons were considered to be customers and their financial capacity thus determined the extent and level of the service that could be called upon. This encouraged a demanding attitude, but it also meant that they had to move out when their money was depleted.

A deliberate choice to move in, however, was rather rare. Many residents had been *forced to move in* (Iwasiw et al. 1996; Fiveash 1998; Hweidi 1999; Andersson et al. 2007; Bland 2007; Bowers et al. 2009; Cooney 2011; Shrestha and Zarit 2012; Chang 2013; Falk et al. 2013; Martinsson et al. 2013; Oosterveld-Vlug et al. 2013b; Teka and Adamek 2014; Stevens et al. 2015; Canham et al. 2016; Mohammadinia et al. 2017). In some cases, they had suddenly lost their functional abilities due to an accident or an acute disease, in other cases they had experienced a gradual decline of self-care abilities, but all of them had had no choice but accept the decision of others. Some older persons were even overrun by such a decision and experienced it as a shock.

> They called my daughter and said that I needed to make up my mind about moving to this place by following Monday at the very latest. This was a Friday afternoon, and I felt unsure… but then I decided to say no, I didn't want to leave my home. My daughter called early that Saturday morning saying that she and her husband were on their way and that I needed to get ready. I didn't understand a word she was saying, and asked what they in God's name were up to? We're moving your furniture today and everything is arranged at the residential care facility for you to move in by Monday, my daughter said. That night my heart was pounding and I couldn't stop crying. (Falk et al. 2013)

Some authors (Eckert et al. 2009; Bowers et al. 2009) even doubt that older people who claimed that it was their own decision to move into a long-term care facility actually had a chance to make a conscious choice, as in most cases they had little time to evaluate a variety of options and to anticipate the consequences of a potential selection. In any case, an involuntary move into a facility did not only mean the loss of control over one's life, it also produced an inner resistance that prevented older persons from recognizing the benefits of staying there, and they were less inclined to make contact with their fellow residents. Some of them needed some time to adapt and to decide to make the best out of their situation while others tended to withdraw although this reinforced their feeling of loss and loneliness.

> My body is like that; my children didn't let me stay at their home. That's why I am here. This is not what I wanted. They forced me to come here. I said nothing. I was dragged like the dead when they wanted me to go. What should I do? So, I have been suffering until now… (Chang 2013)

In cultures where parents expected to be cared for by their children, the move into a nursing home against their will could be a traumatic experience from which older persons did not recover—as it was observed in a residential facility in Nepal:

> During meal time, she did not eat; she only wanted her son. She did not eat. She did not sleep at night. She would just sit there. She did not stay in her room upstairs. … what is the use of to have a son? (Shrestha and Zarit 2012)

Being in such a way abandoned meant to lose control over one's children and not to receive the care that was desired.

5.3.5.3 Environmental Factors

Besides these person-related factors, environmental conditions influenced the satisfaction of social needs. The satisfaction of the desire for distance depended on the *type of accommodation*. Privacy was more or less protected when residents had single rooms or double rooms for couples (Ball et al. 2000; Dobbs 2004; Bergland and Kirkevold 2006; Andersson et al. 2007; Cheng et al. 2011; Bradshaw et al. 2012; Thomas et al. 2013; Shin 2015). However, when such rooms were small, they were more like a prison cell and the residents were forced to spend their time outside (Bright 2007; Murphy et al. 2007). Lack of a private bathroom also restricted privacy (Bergland and Kirkevold 2006). Shared rooms or dormitories, however, meant that privacy was lost—except for some residents who preferred this kind of accommodation (Fiveash 1998; Murphy et al. 2007; Cooney et al. 2009; Cheng et al. 2011; Cooney 2011; Fraher and Coffey 2011; Andrews 2012; Oosterveld-Vlug et al. 2014).

The satisfaction of the desire for closeness, on the other hand, was supported by the existence of *communal space* that allowed for socializing. Dining halls permitted shared meals and created a sense of community (Philpin et al. 2011). A spacious lobby with comfortable seats, recreation rooms, or a café inside the facility were conducive to interaction between residents (Dobbs 2004; Fraher and Coffey 2011; Cheng et al. 2011; Kemp et al. 2012; Sandhu et al. 2013; Andrew and Wilson 2014; Zimmerman et al. 2016). Unfortunately, several facilities had only limited or no communal space (Wu et al. 2009; Cheng et al. 2011; Cooney 2011; Kemp et al. 2012; Canham et al. 2016) and if no common meals were served, residents had less opportunity to socialize (Wright et al. 2010). If common rooms were available, *noise* levels from music or television, from other residents or from staff raising voices or singing along to music made it difficult for residents to hear each other and could cause a communication breakdown (Pryce and Gooberman-Hill 2012). When residents were transferred to a hospital or another facility, *privacy policy* prevented their former friends to stay in contact because staff was not allowed to give information about their whereabouts (Kemp et al. 2012; Zimmerman et al. 2016). *Visitation rules* influenced the contact of residents to friends and family outside. Open visiting hours facilitated their access, whereas restricted time limits for visitations could prevent them from coming (Murphy et al. 2007). Some assisted living facilities had conflicting rules, as information packages indicated that "visiting times are flexible" because the facility was "the home of the resident", while the same documents stated that the residents were "subject to reasonable restrictions on visiting times and places"—a description that remained vague and allowed individual interpretation (Bennett et al. 2015). Obviously, such regulations could have a deterring effect for visitors from outside.

Residents' contact with the outside world also depended on the *connections between facility and environment*. This connection could be facilitated by an open house policy, for example, by inviting neighbours from the surrounding area to participate in joint events (Murphy et al. 2007). If a facility was composed of several buildings, the spatial distance between them resulted in limited contact between their residents (Kuhn 2008; Kemp et al. 2012). Long distances and lack of transportation prevented residents from going out to visit their family or friends and they depended on their visits (Kuhn 2008; Bennett et al. 2015). Some residents, however, told that *access to the internet* would allow them to maintain contacts to families and friends outside (Thomas et al. 2013). Given the increasing diffusion of digital technologies this opportunity is likely to become more important when future generation who grew up with the internet move into long-term care facilities.

In some cases, the *family influenced the social relationships* of the residents. Their children either encouraged them to participate in joint activities (Kemp et al. 2012) or they interfered with contacts they disliked. Sometimes they instructed staff about people who should be prevented from visiting the resident (Bennett et al. 2015), but more often they were concerned about newly formed relationships between couples and tried to separate them (Frankowski and Clark 2009; Villar et al. 2014). As one facility manager observed, some children "become very upset with their mom because Mom was never like this and it's embarrassing for them" (Frankowski and Clark 2009). One reason for the disruption of intimate contacts was the fear of adult children that they might lose their inheritance to the late lover of a parent (Nay 1992).

5.3.5.4 Care for Social Needs

The most influential factor for the satisfaction of social needs, however, was the way how caregivers addressed these needs. Due to their function they held a key position in the social network of the residents. Caring for their social needs depended first and foremost on how they established their own relationship with the residents. Besides they also exerted some influence on the social contacts between the residents.

The relationship of caregiver to residents was often determined by their function and dominated by the performance of certain tasks. It therefore tended to be more task-oriented than person-centred. Task-orientation began with a *formal assessment* to determine to what extent the condition of the residents met required criteria of health and functionality. This was a standard procedure at admission in nursing homes and assisted living facilities (Ball et al. 2004a, b; Kuhn 2008) and it was deemed to be necessary in order to plan the care that was required.

The assessment of care needs was furthermore an ongoing process because care plans could always need a revision due to a deteriorating health condition of the resident. This issue was of particular importance in assisted living facilities, as a certain amount of care needs could exceed the capacity of the facility and the resident had to move into a qualified nursing home. However, since residents in these facilities were officially entitled to autonomy, they could not be subjected to a permanent repetition of such assessments and fearing that they would be transferred to a nursing home against their will, they tried to pretend more self-reliance than they actually had. In reaction, staff members resorted to an *informal monitoring* that could take the character of spying on residents (Kuhn 2008; Williams and Warren 2009: Oakes and Sheehan 2012; Zimmerman et al. 2016). Zimmerman et al. (2016), for example, reported about one staff member, who was aware of the likelihood that his white uniform would make residents pretend to be self-reliant, and who used "tricks" like standing outside and watching through the reflection of the glass door in order to observe residents secretly, and always disappeared quickly so they would not know they are being watched.

Theoretically, decisions about care should be discussed and agreed upon with care recipients—especially in assisted living facilities where residents were considered to be customers who should have choices. In practice, however, staff members *planned care without the resident* based on their observations—even in assisted living. One resident, for example, told about his experiences with care conferences that were standard in many long-term care facilities:

> I will tell you this, I mean no circumstances should they have a meeting about the patient and just have the doctor and the social worker, and the head nurse there and not the patient. Or, someone form the patient's family, that's fine too. But, if the patient's not there, they can say anything or anything and whether it's true or not. And, like the last meeting they had here, I was nowhere to be seen because they never told me they were having anything. (Jordan 2010)

Although intended to obtain a better idea of the needs of residents, such conferences tended in practice to assess these needs without taking their views into consideration. It was in line with this attitude that nurses or caregivers while being on duty rather *discussed about the resident instead of with him* (Koskenniemi et al. 2015), and that the organization *excluded residents from participation in decisions* regarding who was in charge of them and how they could spend their day.

> Well, there would be a lot to do or say, if you could do it your own way. Many times people think it could be otherwise, but it is difficult, and of course it has to be their way. (ibid.)

"Their way" meant that staff *imposed day structure and routines* on the residents (Fiveash 1998; Ball et al. 2000; Koch-Straube 2003; Dobbs 2004; Al-Omari et al. 2005; Bland 2007; Hellström and Sarvimäki 2007a, b; Murphy et al. 2007; Hauge and Heggen 2008; Tsai and Tsai 2008; Williams and Warren 2008; Timonen and O'Dwyer 2009; Cooney 2011; Park et al. 2012; Chang 2013; Hwang et al. 2013; Gustavsson et al. 2015; Bollig et al. 2016; Heid et al. 2016; Naess et al. 2016; Tuominen et al. 2016). Long-term care facilities had a fixed schedule that set the time for waking up, meals, therapies, and participation in joint activities and residents were expected to adapt to it. Such schedules could also determine the day when residents had to take a shower and the amount of time that was available for a particular activity. Even in assisted living facilities that intended to ensure self-determination such schedules existed and gave residents a feeling of being imprisoned as rules and schedules determined their daily life (Park et al. 2012).

> Although I don't want to wake up in the morning, I have to wake up and have breakfast, because it's one of the rules of communal life. (Chang 2013)

> They clean the table before the meal is finished…. [You need] a respectable time to eat your meals…. You feel like you are in school. (Timonen and O'Dwyer 2009)

In such a framework, care was reduced to the *repeated performance of tasks* (Bland 2007; Chuang and Abbey 2009; Wilson and Davies 2009; Fraher and Coffey 2011; Koskenniemi et al. 2015; Naess et al. 2016). The caregivers were mainly concerned with doing their job in a fast and effective way. As one of them told:

> Right after you begin to work, you just want to finish the assigned tasks as soon as possible. That's your job (Chuang and Abbey 2009)

Routine procedures offered a way to reduce the workload by diminishing the necessity to adapt to changing circumstances. At the same time, they should ensure that duties were carried out thoroughly. As one caregiver explained:

> Well if you didn't have a routine, you wouldn't get the jobs done, like getting them washed and dressed in the morning and getting them to breakfast for a certain time or making sure the pads are changed because if they get into that routine and if it is a certain time then you don't forget. (Wilson and Davies 2009)

The residents were, of course, aware of the time pressure under which care was provided and felt forced to adapt accordingly.

> The nurses are too quick for me, and I am not able for it. It's probably their age; they would be dressing me too quick. I suppose they have so much to do. (Fraher and Coffey 2011)

Under these circumstances, no consideration could be given to the special requests of particular residents. Care assistants, who had been sent to support them, provided *care as prescribed*, but nothing more:

> One day she come in, cleaned me and washed my clothes, everything. And I'd had to use a bedpan. So I said to her, 'Would she empty it?' 'I haven't come here to empty your pot, I've come here to get your tea,' she says. 'You want to ring the warden if you want her to empty it or ring the Careline'. (Wright et al. 2010)

This attitude was associated with a *lack of communication with the resident* which prevented them from establishing a closer relationship with their caregivers that allowed them expressing their wishes (Coughlan and Ward 2007; Westin and Danielson 2007; Bowers et al. 2009; Hwang et al. 2013; Taylor et al. 2014)

> They approach you in such a way that you feel you are actually being ignored – yes, you do not exist – you are just like a ghost, nothing else. (Westin and Danielson 2007)

In nursing homes, there was a tacit *dominance of medical care* underlying this task-oriented attitude. Some researchers (Wu and Barker 2008: Nakrem 2015) observed that the nursing staff focused on treating the medical diagnoses of the residents and that they defined the quality of care in terms of biomedical results. For example, during meals they were mainly busy administering medication and ensuring sufficient food intake, and at meetings they emphasized physical problems, such as pain, difficult breathing, defecation, problems in getting up from bed, the amount of food eaten, etc.

Task-oriented care was associated with *overprotection* (Koch-Straube 2003; Wilson and Davies 2009; Wright et al. 2010; Oakes and Sheehan 2012; Barnes et al. 2013; Naess et al. 2016). Caregivers, for example, restricted the mobility of residents in order to prevent accidents that would also cause more work for them.

> We have four staff on constantly watching the residents. You have to be thinking about it (safety) at all times. So if a resident gets up and you know they're prone to falls you'll sit them back down, that way there's less accidents. (Wilson and Davies 2009)

This attitude increased residents dependency as caregivers provided unnecessary support that on the short run saved some time:

> But there is the cost thing, about how much longer it takes to sort of encourage someone to walk down to the restaurant for lunch, rather than sticking them in a wheelchair and wheeling them down. (Wright et al. 2010)

On the long run, however, such unnecessary care increased their workload as residents unlearned their self-reliance. Overprotection was embedded in *safety regulations* that restricted the self-determination of residents (Hweidi 1999; Ball et al. 2004b; Al-Omari et al. 2005; Dobbs et al. 2008; Williams and Warren 2008; Eckert et al. 2009; Oakes and Sheehan 2012). Even in assisted living facilities, despite their agreed upon independence, residents had to accept supervision over their self-care activities and they were not allowed to consume alcohol or to smoke in their rooms—although these were considered their private homes.

> Do you know that [facility staff] saw me—I bought an extra thing of Tylenol at the grocery store— and she said, 'you have to put that in the nurse's office. (Dobbs et al. 2008)

To enforce compliance with rules and directives caregivers tried to *educate and control* the residents (Koch-Straube 2003; Dobbs 2004; Hellström and Sarvimäki 2007a, b; Williams and Warren 2008, 2009; Oakes and Sheehan 2012; Zimmerman et al. 2016). They told them when to get up (in one facility they even gave instructions via loudspeakers (Williams and Warren 2008)), prevented them from going to bed when time did not seem appropriate, reprimanded them for inappropriate behaviour in front of others, and threatened to transfer them to a nursing home. Education and control of residents was often associated with a *bossy and rude behaviour* (Jordan 2010; Oosterveld-Vlug et al. 2014; Roberts and Bowers 2015). One resident, for example, described a nurse in the following way:

> There's an older [nurse] and she comes at night and all I can think of is the description of her was an army nurse. (Roberts and Bowers 2015)

And another resident recalled an incident that occurred when he asked a nurse to get his medication earlier than scheduled:

> I had to catch an 8 o'clock bus, I knew that. So, I went to her and uh I told her, I says I have to catch an 8 o'clock bus, can I have my medication […] And, they usually give it to us about 8 o'clock so I wanted my medication early. Well, she didn't understand my feelings of it and she uh-she lost her cool. So, she did in a very, very loud voice, she did speak up really harshly to me. And, this didn't-this didn't just uh-didn't last for just a minute or so, this continued on and on and on for I don't know how-a definite time anyway. (Jordan 2010)

Some residents also complained about a *rough treatment* when they received care, and some even feared to be abused one day (Fiveash 1998; Tsai and Tsai 2008; Hwang et al. 2013; Gustavsson et al. 2015).

> Some are a bit rough, they don't always understand that you are 97 and fragile (Gustavsson et al. 2015)

Caregivers were not always rough in their treatment of the residents, more often they were only *inattentive* and did not realize that there were unspoken needs (Grau et al. 1995; Sidenvall 1999; Andersson et al. 2007; Coughlan and Ward 2007; Williams and Warren 2009; Jordan 2010; Chang 2013; James et al. 2014; Bollig et al. 2016; Cho et al. 2017). They overlooked the pain someone was suffering from, and they disregarded his emotional condition.

> They ain't no concern how you feel or nothing else. They don't know if you had a bad day or not. […] They ignore that in the conversation, it doesn't matter. (Jordan 2010)

Sometimes caregivers were distracted by other, apparently more attractive activities like watching TV while providing care. One resident complained:

> These are young girls who are not used to this … and if the television is on… they concentrate on the film and forget to feed me. (Bollig et al. 2016)

Others, however, were rather annoyed by having permanently to pay attention to the demands of the residents. Residents believed that they were *reluctant to provide help* and that they made them wait on purpose (Grau et al. 1995; Bowers et al. 2001; Coughlan and Ward 2007; Cooney et al. 2009; Timonen and O'Dwyer 2009; Falk et al. 2013; Taylor et al. 2014; Bollig et al. 2016)

> It's not that they're so busy…you know…sometimes they're just standing around…they want to make sure we know our place…[and] know who's in charge (Bowers et al. 2001)

> They do it on purpose, you know… [making us wait] gives them a feeling of power.(ibid.)

Caregivers sometimes justified the rejection of requests by arguing that these were not legitimate as residents were still capable of performing the required tasks (Oakes and Sheehan 2012). However, there were also situations when the behaviour of the residents caused the caregivers to *keep their distance*. Sometimes they felt the resistance of the residents which caused them to hold back (Ball et al. 2009). Female caregivers also had to take precautions not to give the perception of impropriety when caring for male residents (ibid.) since this could provoke sexual adavances that were shocking and embarassing for them (Nay 1992).

Besides a task-orientation, there was also person-centred care which had a positive effect on the social well-being of the residents. Some facilities managed to plan care together with residents so that they could express their own needs and expectations.

> They have a plan laid out. I would assume that applies to people who are sick differently one from another. And, I know in my case, at a meeting and I was there. And it was a matter of preparing for bed or getting up in the morning. And I said: 'Well, I', I explained the things I can't do and I would like covered. And they drew up a statement from the R.N. to the effect that when you get up in the morning you can wash your face and hands, and they would bring the water to you. (Grant et al. 1996)

In order to reach *agreements on care and safety rules*, assisted living facilities negotiated service contracts that described in detail the services to be provided and risk agreements in which residents who engaged in risky practices indicated their understanding of risks and agreed to take responsibility for negative outcomes (Carder 2002; Al-Omari et al. 2005).

Besides such formal agreements, there were also attempts to provide person-centred care in daily practice. Some facilities *offered small choices*, for example, by bringing a variety of desserts into the dining room on a trolley enabling residents to make their selection on the spot (Barnes et al. 2013). Some caregivers had flexible routines to *adapt to the wishes and needs* of the residents (Grant et al. 1996; Barnes et al. 2013; Hwang et al. 2013; Koskenniemi et al. 2015; Tuominen et al. 2016). They postponed, for example, meals or washing times if residents asked for it or they consulted them about the portion sizes when plating food.

> I can do my own things leisurely – I don't have to stop my tasks suddenly. They (nurses) come to me and tell that it's coffee time and you can come to the living room when you are ready. I don't have to go there immediately. (Koskenniemi et al. 2015)

Some facilities also showed *flexibility in the applications of rules* (Al-Omari et al. 2005: Palacios-Ceña et al. 2013). They allowed, for example, that residents changed assigned seats in the dining room or that they left without signing the sign-out book as it was required according to the regulations of the facility.

Flexibility allowed caregivers to *become familiar with the personal routines* of the residents and to adapt to them so that after some time residents no longer had to communicate their needs as the caregivers already knew them (Murphy et al. 2007; Ball et al. 2009; Wilson and Davies 2009; Jordan 2010) As one caregiver explained:

> Well everyone has a personal routine and you get to know when they like to get up or go to bed, or if they need a rest in the afternoon. Like now, it's getting near 10 so I know that James will need to go to the toilet, so I'll take him next. (Wilson and Davies 2009)

Prior to such tacit understanding, *attentiveness to the residents* was required (Al-Omari 2005; Jordan 2010; Oosterveld-Vlug et al. 2013b). This did not only mean to listen to their desires, it also implied to look after them in order to discover their unmet needs:

> Oh yeah, I had another one of the nurses last night. I didn't go to supper, she came walking right here. I didn't go to eat supper at all because I was still in bed. She comes in and asks Mr. XXX is something wrong. I said no. I said they ain't had anything I wanted to eat so I didn't go. She said will I didn't know, I thought you were sick. (Jordan 2010)

A further aspect of person-centredness was to provide *care in time* and helping residents as soon as they were in need (Tsai and Tsai 2008; Hwang et al. 2013; Tuominen et al. 2016). Not having to wait gave residents a feeling of being cared for while exerting some control at the same time. *Small favours* by the staff like bringing a little present also contributed to a feeling of being cared for (Al-Omari et al. 2005; Murphy et al. 2007; Wilson and Davies 2009; Schenk et al. 2013; Thomas et al. 2013). One resident recalled such an instant.

> There was the maintenance man who said one day, 'I have a comfortable chair you can have because you always sit here'. I thought he was joking… but then one day, it was there…it looked new….when I saw the man again I told him thank you. (Thomas et al. 2013)

Such favours were also useful to establish a closer relationship to the resident. Caregivers used a variety of strategies to achieve this aim. *Chat and small talk* promoted a positive social climate and indicated that caregivers were interested in the personality of the resident (Coughlan and Ward 2007; Murphy et al. 2007; Cooney et al. 2009; Hwang et al. 2013; Oosterveld-Vlug et al. 2013b; Nakrem 2015; Cho et al. 2017).

> I've visited nursing homes before we came in you know, visiting neighbours and there was all, there was nobody talking to anybody… It's different here, the nurses come up there, they just come up for a bit of slag… (Murphy et al. 2007)

Making jokes created a more open and relaxed atmosphere. Small talk while providing personal care also helped to mask feelings of shame. Such close contact entailed that several caregivers *reduced their distance* to the residents and became involved in a more private relationship (Murphy 2007; Hauge and Heggen 2008; Heliker 2009; Cooney 2011; Nakrem et al. 2011; Nakrem 2015). They called them by their first names, if the residents desired, took their lunch in the common room, and shared with them their private affairs. Some of them also visited the residents in their private room to spend time by talking (Naess et al. 2016) and one caregiver even brought her own children into the facility to join a celebration of Halloween (Murphy 2007). Such incidents gave residents the feeling that they had forged a special relationship with their caregivers and if one of them told about her personal troubles they were able to reciprocate and give some advice. Closeness could be reinforced when caregivers *showed their empathy* by approaching the resident with affection, speaking kind words, maintaining eye contact, and by establishing physical contacts through holding hands or giving a kiss or a hug, provided the resident accepted it (Grant et al. 1996; Bland 2007; Coughlan and Ward 2007; Murphy 2007;

Nakrem et al. 2011; Figueredo-Borda and Zabalegui-Yárnoz 2015; Koskenniemi et al. 2015; Nakrem 2015). In this way, caregivers *developed a relationship of trust* that also allowed residents to share their private affairs with them and to establish a family like relationship that satisfied their desire for closeness (Al-Omari et al. 2005; Coughlan and Ward 2007; Bradshaw et al. 2012; Oakes and Sheehan 2012; Behr et al. 2013; Hwang et al. 2013; Adra et al. 2015).

If caregivers succeeded in establishing a personal relationship with residents, they could influence them without exerting pressure and control. Mutual sympathy allowed them to *persuade the residents* to co-operate should they be unwilling to do so.

> Usually, we try to be more than just staff working here. We try to be their friends. We try to comfort them a lot. We try to sit one-on-one with them, you know, make eye contact, and let them know we care about them, and like, the way we care… So we hardly have days where people refuse. We always get them to do it…somehow. (Oakes and Sheehan 2012)

For the same reason, some caregivers *searched the dialogue* with the so-called difficult residents who tended to be non-compliant or demanding.

> Sometimes, just sometimes by talking to them, there are often some patients, sometimes they're difficult, they can be very difficult, but you usually find with difficult patients if you sit down and talk to them then they tend to become less sort of difficult and they start to trust you I suppose as well (Murphy 2007)

Caregivers also made efforts to *promote the self-reliance* of the residents by encouraging their self-care (Ball et al. 2004a; Murphy et al. 2007; Koskenniemi et al. 2015). At the same time, however, they had to pay attention to their needs so that they did not feel neglected:

> We will not do anything for them they can do on their own. If they need us we're there. If they need assistance with bathing, we'll assist, but I tell the staff if all they need is for you to run the water for them and you assist them in the tub, let them bathe themselves. Don't make them more dependent than they have to. (Ball et al. 2004b)

Procuring assistive devices like shower stools or special dishes supported these attempts. Caregivers also made efforts to *respect and protect the privacy* of the residents (Bauer et al. 2013; Oosterveld-Vlug et al. 2013a, b; Oosterveld-Vlug et al. 2014; Figueredo-Borda and Zabalegui-Yárnoz 2015). At least some of them got used to knock at their door before entering and to prevent others from watching how they provided personal care.

> I think you should do everything you can to safeguard privacy. So if you are busy washing someone, keep the door closed. And when you come in you cover them with a sheet. (Figueredo-Borda and Zabalegui-Yárnoz 2015)

In addition to establishing their own relationship with the residents, the caregivers also influenced the relationships that existed between the residents. This influence began at the admission. As already mentioned above, assisted living facilities made *attempts to* *select residents* who fitted well with the culture of the home in order to meet expectations of those who already stayed there (Kuhn 2008; Perkins et al. 2012). Selection criteria were the degree of functional limitations and social status. This produced a certain homogenization of the residents that facilitated relationships among them. However, since vacancies had to be avoided, older persons who were deemed less suitable also had to be accepted. Social harmony, of course, could be restored by the *discharge of residents* who were perceived as disturbing (Kemp et al. 2016).

After admission, it was necessary to *promote the integration of newcomers* (Al-Omari et al. 2005; Heliker and Scholler-Jaquish 2006; Kemp et al. 2012; Shaw et al. 2016). There was a variety of ways to achieve this. New residents were introduced and welcomed in meetings and—if existing—in the newsletter of the facility. In some facilities, they were also paired with "buddies" to make them familiar with new place, and caregivers interfered sometimes on their behalf if other residents were reluctant to accept them. To some extent, staff also *arranged contacts* among individual residents by encouraging interaction between those they considered to be like-minded (Cooney et al. 2009; Wilson and Davies 2009; Kemp et al. 2012; Sandhu et al. 2013). One caregiver, for example, told:

> I try to group them where they'll be with their own kind, a little group of people that they can have something in common together. (Kemp et al. 2012)

Caregivers also tried to *facilitate communication* in larger groups of residents, by gathering them in common areas and starting a conversation (Hauge and Heggen 2008; Cooney 2011; Kemp et al. 2012; Gustavsson et al. 2015; Zimmerman et al. 2016). However, such attempts could also fail, when the caregivers left them to themselves and the residents felt that they had nothing to talk about. Those who were still mobile then went back to their rooms, while those who suffered from impaired mobility had no choice but to stay and retreat into silence (Koch-Straube 2003; Hauge and Heggen 2008; Gustavsson et al. 2015; Christov 2016). In order to avoid such reactions, one nursing home tried to elicit social contacts by *simulating real life situations*. A rolling kiosk gave residents the opportunity to purchase candy and cookies that they could share with their roommates, which created a situation that prompted conversation (Naess et al. 2016).

However, the most important way to promote social contacts was to arrange social events. *Common meals* were an integral part of long-term care facilities and ensured that their residents met regularly (Sidenvall et al. 1994; Fiveash 1998; Al-Omari et al. 2005; Wright et al. 2010; Philpin et al. 2011; Andrews 2012; Kemp et al. 2012; Park et al. 2012; Perkins et al. 2013; Zimmerman et al. 2016). Eating together created social bonds between residents. The impact of common meals on social relationships depended, however, on the way how they were organized. In some facilities, participation was optional (Al-Omari et al. 2005). This gave residents a feeling of independence, but it could also reinforce social withdrawal that resulted in isolation. In most facilities, however, participation was rather compulsory. This could result in the establishment of relationships, but also force residents to make contacts they did not want.

Social contacts at mealtimes were stimulated by an appealing atmosphere. Philpin et al. (2011) described an arrangement they labelled as "family-style" where "residents ate at small, four-seater dining tables, pleasantly laid with linen cloths and napkins, pretty china and flowers" which was conducive to communication. *Family-style service* at mealtimes could also increase the sense of self-reliance and control by offering some choice. Barnes et al. (2013) observed two ways of such family-style service: Food was presented in serving dishes and placed on each table so residents could either help themselves, with staff supporting those who were not able to self-serve, or a chef was present in the dining room with the available choices on a hotplate and served food for each person individually as desired.

Contact opportunities at mealtimes depended furthermore on *seating arrangements* made by caregivers. In many facilities, residents were not allowed to choose their place. The personnel decided where and with whom each resident had to sit. Such arrangements should ensure social harmony. Quarrelsome residents were separated and calm residents were placed in tables where conflicts existed in order to reduce tensions (Palacios-Ceña et al. 2013; Naess et al. 2016). As one resident told:

> Since I am calm, they place me where there is trouble, to cool things down. (Palacios-Ceña et al. 2013)

In this way seating arrangements promoted positive relationships, but they also prevented residents from establishing contacts of their own choice. Another purpose of these arrangements was to separate self-reliant residents from those who were unable to observe table manners due to their impairments. The idea behind this separation was that it might be annoying for able-bodied residents if they had to witness the incompetence of others (Sidenvall et al. 1994; Kemp et al. 2016; Naess et al. 2016).

Besides the arrangement of common meals caregivers were also involved in the *organization of joint activities* (Ball et al. 2000; Koch-Straube 2003; Al-Omari et al. 2005; Kennedy et al. 2005; Murphy 2007; Williams and Warren 2008; Eckert et al. 2009; Svidén et al. 2009; Bradshaw et al. 2012; Kemp et al. 2012; Park et al. 2012; Hwang et al. 2013; Sandhu et al. 2013; Teka and Adamek 2014; Gustavsson et al. 2015; Naess et al. 2016). In order to ensure participation there were different ways of *inviting residents* like distribution of daily activity schedules at breakfast, daily postings on boards in the lobbies, phone calls to residents, hand-delivered invitations, and friendly reminders (Iwasiw et al. 2003; Al-Omari et al. 2005; Kemp et al. 2012; Gustavsson et al. 2015; Naess et al. 2016). One staff member described his way to get residents to the program:

> Knock on the doors, give them a warm smile and tell them 'come for a little while you might have fun'. (Al-Omari et al. 2005)

Some residents felt welcomed and respected if they were personally invited (Iwasiw et al. 2003). Others, however, felt that such well-meant *expectations to participate and socialize* compelled them to participate in activities they actually disliked (Hjaltadóttir and Gustafsdóttir 2007; Hauge and Heggen 2008; Warren and Williams 2008; Williams and Warren 2008; Jordan 2010). There were older persons in assisted living facilities who believed that joint activities were a means of assessing their functional capacities and as they feared to be transferred to a nursing home they complied with such expectations. In any case, participation meant that they had to observe a certain dress code and to adapt to a programme that suited the average resident but did not meet their individual needs.

> And also there is a lack of many or most of getting to know the individual person and they try to treat you as a group. Instead of treating you as individuals and that's something they have to be trained in and they have to learn. Everybody is different. […] You have to be able not to treat people as a group. (Jordan 2010)

One reason for the failure to meet individual needs was a limited knowledge about the residents and their preferences. Another reason was that activity staff included short-term volunteers or part-time staff with limited experience (Kemp et al. 2012).

In some facilities, contacts between residents seemed to be welcome only if staff was able to control them, and there were residents who complained about *restrictions on mutual visits*.

> I wish it was just open where we could walk in each other's room and talk. But it's not! Everyone has their room. And they [staff] don't want you— they tell us not to open 'em. Or knock on them. (Park et al. 2012)

Staff also had an influence on the social relationships between residents and their families and friends outside the facility. Some facilities *involved significant others* in the care of their residents (Grant et al. 1996; Holmgren et al. 2013; O'Shea et al. 2014; Koskenniemi et al. 2015). Significant others were able to provide information about the preferences and lifestyle of the older persons and to advocate for them. Interfering in the process of care allowed them to maintain a positive relationship with the residents and to take care of them. Such interference, however, was not always welcome. Some caregivers perceived it as an intrusion into their work and tried to reduce their influence:

> My God, they can be involved in what the residents should wear or what they should eat for dinner… but somehow the relatives forget that we are experts in caring and they are not. But then again, they think that they know their mom or dad for whom we are caring and I can understand that. But that was when they were healthy, not now… (Holmgren et al. 2013)

There were also facilities that *restricted visits from families and friends* (Bennett et al. 2015). If these were viewed as some sort of burden or as an impediment to medical or institutional routine, they became unwanted guests in the minds of the staff. Unspoken rules about guests and what they were permitted to do created an uncomfortable atmosphere and kept outsiders away. For example, visitors were expected to register and staff could disturb the privacy of their visit by observing it. Staff also *prevented intimate relationships*, even among married couples, by criticizing the behaviour of the residents or simply by forbidding it (Dobbs et al. 2008; Frankowski and Clark 2009; Bennett et al. 2015). Others facilities, however, tried to *provide a discreet environment for intimate relationships* so that residents remained undisturbed and did not offend others (Naess et al. 2016).

5.3.6 Behavioural and Attitudinal Reactions

If the residents were unable to satisfy a certain orientation of action, they tried to cope with this situation. This concerned, on the one hand, their relationship with the caregivers, on the other hand, their relationship with the roommates. Their relationship with the caregivers was mainly based on their care needs. Residents who lacked self-reliance *asked for help*. Underlying this care seeking behaviour was an increasing *acceptance of care dependency* which was an expression of a critical self-perception that we will take a closer look at when describing the identity-related orientations of action (Grau et al. 1995; Walker and Curry 2007; Fraher and Coffey 2011; Oosterveld-Vlug et al. 2013a; Taylor et al. 2014).

To receive the care and support they desired some residents made efforts to establish a close relationship to their caregivers. They engaged in *small talk* with them (Cooney 2011) and *expressed their appreciation* (Bland 2007; Jordan 2010; Roberts and Bowers 2015).

> I know I make it a point to know them al by their first names and I make efforts-some little thing, I may offer them a piece of candy or some little treat. I try to keep little treats in my room that I offer because I appreciate them so much. (Jordan 2010)

Sharing private matters with caregivers gave residents a sense of familiarity and satisfied their desire for closeness (Grau et al. 1995; Nakrem et al. 2011; Adra et al. 2015). For this purpose they liked to choose a confidant whom they saw as having their best interest at heart, and acting on their own initiative:

> I like all of the nurse aides and I have some favourites that I talk about everything with – out families, our friends, what we like to do… it's like getting to know family. (Grau et al. 1995)

Not all residents, however, were inclined to establish a positive relationship with staff. Some tried to satisfy their need to be cared for by exerting control. These residents were *demanding and complaining* (Dobbs 2004; Ball et al. 2009; Williams and Warren 2009; Speller and Tollee 2015). They viewed caregivers as incompetent and treated them like servants. Dobbs (2004), for example, observed residents in assisted living who claimed that the food was always horrible, and that the staff was always late with dinner; that caregivers did turn the thermostats too high or too low in rooms, and did just care about getting a pay check. In some cases white residents in assisted living facilities even showed open *racism* against their black caregivers (Ball et al. 2009; Williams and Warren 2009; Kemp et al. 2012; Park et al. 2013). Some refused to be bathed by them (Park et al. 2013), while others insulted them with racial expressions like "coloured girl" or the "nword" (Ball et al. 2009).

> This one … kept on telling me, 'What are you doing in this country? … you know you are abusing our money. We don't want you here. Go back to your country' (Williams and Warren 2009)

Such behaviour reflected also the gulf of social status between working, poor staff and upper middle to middle class older persons who could afford to pay for staying in a hotel-like facility where residents had to be treated as customers. It was mainly observed in assisted living which was made for residents who were less care dependent and had a higher socio-economic status that enabled them to dominate staff to some extent. As one caregiver explained:

> But [they were] still financially better than we were. And they think they pay a lot of money to live here, they have a right to treat you the way they want to. (Williams and Warren 2009)

In some cases, upper-class residents perceived care in nursing homes as inadequate and *hired additional staff* to meet their expectations:

> I have someone especially for me, I give her a salary and pay her extra, they [the management of the nursing home] gave me the permission that she stays with me. (Boggatz et al. 2009)

An agreement as in the above example from Egypt was based on the common practice in this country that care dependent person had to be cared for by relatives or privately paid caregivers as their substitutes when they were in a hospital—a practice that also could be applied to receiving care in nursing homes.

In contrast to these residents, there were also those who wanted to maintain their self-reliance and *rejected help* even if the staff was worried about them and willing to help (Ball et al. 2004b; Hillcoat-Nalletamby 2014). Out of a desire to remain in control other residents *rejected well-meant advices* for their well-being and health, ignored regulations of the facilities and did as they liked (Koch-Straube 2003; Oakes and Sheehan 2012; Martinsson et al. 2013; Palacios-Ceña et al. 2016a).

The attempt to exert control could result in a power struggle where caregivers in turn tried to impose care on the residents. In such situations, the residents tried to *resist against care* (Grau et al. 1995; Koch-Straube 2003; Al-Omari et al. 2005; Ball et al. 2009; Cooney 2011; Tuominen et al. 2016). Some reacted with open aggression which consisted of verbal abuse and sometimes also physical violence such as kicking or biting in order to defend themselves. Others resorted to passive resistance and refused to eat or talk.

> There are days I decide I'm not getting up. (Staff ask) me 'are you getting up today?' No. … I defy anyone to move me when I make up my mind. (Cooney 2011)

With diminishing strength, however, residents were doomed to lose this power struggle and as they saw no opportunity to change anything they finally *gave in.*

The ensuing experience of powerlessness made residents abandon their desire for control and resulted in *subordination* to their caregivers (Grau et al. 1995; Fiveash 1998; Sidenvall 1999; Iwasiw et al. 1996; Koch-Straube 2003; Hellström and Sarvimäki 2007a, b; Tucket 2007; Wu and Barker 2008; Chuang and Abbey 2009; Timonen and O'Dwyer 2009; Chang 2013; Falk et al. 2013; Hwang et al. 2013; Taylor et al. 2014; Bollig et al. 2016; Donnelly and MacEntee 2016; Tuominen et al. 2016). They adapted to imposed schedules and routines, showed no interest in having choices, and withheld complaints in case of substandard care—sometimes because they felt that complaints would be useless, and sometimes out of fear from negative consequences.

> I don't want to say anything to make trouble and make the relationships worse. If it is not gone too far and I still can tolerate it, I will make no complaint (Chuang and Abbey 2009)

> Just keep quiet and that's it … the fear of causing trouble … that is what it is, isn't it. Fear of causing trouble and there is a backlash on you. (Timonen and O'Dwyer 2009)

One resident was even worried that complaints might prompt the owners to close the facility "and sell us all to somebody else" because they might feel that "it is not worth it for the bits and pieces that they get out of it" (Donnelly and MacEntee 2016).

Some nursing home residents believed that the only way to get caregivers to comply with some of their wishes was to be humble and polite or obedient (Iwasiw et al. 1996; Tuominen et al. 2016). Their subordination also became apparent when they expressed their gratitude for a care they actually found unsatisfactory (Nakrem et al. 2013; Bollig et al. 2016). Knowing to be dependent on their help made them avoid criticism of caregivers and respond in a socially desirable way during interviews (Christov 2016). The same tendency was observed in assisted living facilities where fear to be moved into a nursing home made residents comply with imposed care (Warren and Williams 2008). For this reason some authors warn against interpreting residents' statements of gratefulness as a satisfaction of their desire to be cared for (Sidenvall 1999). Other authors, however, interpret the *avoidance of complaints* as a way to pay attention to the needs of caregivers who were under time pressure and suffered from high workload (Hellström and Sarvimäki 2007a; Speller and Tollee 2015). In this sense, compliance was a strategy to build a positive relationship with caregivers in the hope that this would be reciprocated.

The relationship between residents and roommates was mainly based on the desire for closeness and distance. To establish relationships, the residents *engaged in conversation* with each other (Hweidi 1999; Hubbard et al. 2003; Heliker and Scholler-Jaquish 2006; Hauge and Heggen 2008; Curle and Keller 2010; Kemp et al. 2012; Roberts and Bowers 2015). Topics were often superficial including the weather or how one was doing. They also spoke about other people, including their families, other residents, and staff, or they discussed about the past, television, sports, religion, and politics. At mealtimes food was a common topic. Joking, flirting, and teasing were often part of such conversations. Koch-Straube (2003) observed conversations that seemed to be trivial but had a hidden meaning. For example, a dialogue between a male and a female resident about who might be the owner of some glasses lying on a table nearby was also an attempt by the male resident to make closer contact which was rejected by the female resident by claiming that these glasses originally belonged to her late husband.

To gain the sympathy of their roommates, they passed compliments and *showed their affection* by smiling, giving thanks, or shaking hands (Hubbard et al. 2003; Curle and Keller 2010). To some extent residents also gave each other *assistance and emotional support* (Iwasiw et al. 1996; Williams and Warren 2009; Curle and Keller 2010; Philpin et al. 2011; Kemp et al. 2012; Park et al. 2013; Thomas et al. 2013; Behr et al. 2014). They helped others to sit down or stand up, moved obstacles like walkers out of their way, passed items out of reach, or encouraged others to finish their meal. Some made efforts to involve roommates who suffered from impaired hearing or from dementia into a conversation. They also encouraged others and comforted those who experienced losses and were grieving.

However, the residents did not show the same affinity to each of their roommates. They rather tended to *form groups* whose members felt connected while at the same time excluding others from their circle (Hubbard et al. 2003; Nakrem et al. 2011; Philpin et al. 2011; Kemp et al. 2012; Park et al. 2012; Perkins et al. 2012; Palacios-Ceña et al. 2013; Sandhu et al. 2013; Thomas et al. 2013; Zimmerman et al. 2016). In this way, their closeness to some residents created at the same time a distance to others. Therefore there was also communicative behaviour by which they tried to exclude and control others. *Gossip* was a way to subject others to a critical evaluation (Perkins et al. 2012). It forged closer ties among those engaged in it and made them feel superior to those who were exposed to it who in turn felt excluded. When the residents felt disturbed by others, they either *reprimanded* them directly or they expressed their annoyance non-verbally to enforce their adjustment to social norms (Dobbs 2004; Christov 2016). Some demanded that disturbing residents should be separated from “normal people” and transferred to a higher level of care. In any case, most residents *shunned persons with dementia or other impairments* (Hweidi 1999; Hauge and Heggen 2008; Kemp et al. 2012; Perkins et al. 2012). Sometimes, residents felt annoyed by others and began to *quarrel* (Kemp et al. 2012; Perkins et al. 2013; Sandhu et al. 2013). Kemp et al. (2012), for example, observed the following situation that occurred at a joint activity: “Irving said something to Hillary and she told him, ‘Get away you slob!’ A staff person [told him] to go on the other side of the room … Irving started aggravating Hillary from across the room. He yelled out to Hillary, ‘Hey Chubby.’” Some conflicts were rooted in interethnic tensions as they were observed in American facilities with a mixture of ethnic groups (Park et al. 2013). As mentioned above, conflicts sometimes involved physical violence by residents against each other (Boggatz et al. 2009).

Due to such conflicts and dislikes, it was not surprising that there were residents who *avoided contact with all their roommates*, with whom they had to live together without wanting it. In some facilities, these residents were rather outsiders, as the majority was inclined to socialize. In other facilities this behaviour was so pervasive that the main feature of communal life was silence (Koch-Straube 2003; Christov 2016). In some cases, this avoidance was not due to dislike but due to feelings of shame because the resident suffered from incontinence or diarrhoea and felt unable to adjust to standards of acceptable behaviour (Jordan 2010). Some of these residents tried at least to uphold social manners and their behaviour was characterized by *formal politeness*.

> Right now I really have no relationships other than greeting them. (Kemp et al. 2012)

Those who were still mobile *left sometimes the facility* (Park et al. 2009; Svidén et al. 2009; Shaw et al. 2016). This allowed them maintaining contacts to persons outside and—if they felt uncomfortable in their social environment—escaping for a short time from a place they disliked.

5.4 Long-Term Care Facilities and Identity-Related Orientations of Action

Long-term care facilities frame the entire life of their residents. They influence not only the satisfaction of body-related and social needs but also the way in which residents can unfold their identity. They may or may not offer opportunities for work or relaxation, diversion or reflection, self-centredness or concern for others, self-presentation or self-concealment, and for a positive or a critical self-perception. Table 5.5 provides an overview over these identity-related orientations of action, their satisfaction, their influencing factors, and the behavioural and attitudinal reactions of the residents.

5.4.1 Work Versus Relaxation

5.4.1.1 Work

Living in their own home necessitated older persons to perform a variety of activities. They had to care for themselves and their household. Although they were retired, they still had to work. This could be strenuous, but it also gave them something to do and filled their time. These tasks, however, were lost by moving to a long-term care facility. As residents they nevertheless had a *desire to be busy* and active (Bland 2007; Stathi and Simey 2007; Chin and Quine 2012; Adra et al. 2015; Slettebo et al. 2016). Some residents remained unspecific about the kind of activity they wanted to perform, others showed a clear *desire to work* and to be productive—even if this just meant that they contributed somehow to the work that had to be done in the facility (Ball et al. 2004b; Hutchinson et al. 2011; Chang 2013, Falk et al. 2013; Palacios-Ceña et al. 2016a).

> I asked them to give me some work for the home, to fix things. (Palacios-Ceña et al. 2016a)

> I would like to find something that I can do. Why can't I bring a pot and boil soybeans this fall? I wish I could make soybean paste and red pepper paste… I think there must be skilful people here. (Chang 2013)

Another resident gave a rationale for this desire:

> I have worked all my life. I have always had responsibilities, and suddenly I find myself here, with my wife, I feel useless, I need to do something. (ibid.)

If these residents had no chance to do something in the facility, they engaged in domestic chores within their private sphere, such as dusting bookshelves, polishing old photographs or silverware, and doing some light housework—provided they had a room they could furnish themselves. Beside this desire for practical work, there was also a *desire for productive leisure activities* that facilitated self-expression through mental and physical engagement (Harmer and Orrell 2008; Hutchinson

Table 5.5 Identity-related orientations of action, influencing factors, behavioural and attitudinal reactions

Orientations of action and their satisfaction	
Work	Desire to be busy
	Interest to work
	Desire for productive leisure activity
	Desire for mental challenge
	Easy activities that match abilities
Satisfaction of work	Enjoying being active
	Having nothing to do
	Having achieved nothing
Mental relaxation	Desire for idleness
	Calming down the mind
Satisfaction of mental relaxation	Rest and relaxation
	Enjoyment of nature
	Feeling overburdened
	Unable to relax because of rumination
Diversion	Desire for collective amusement
	Desire for an increased stimulation
	Desire for individual entertainment
Satisfaction of diversion	Pleasure in social activities
	Joy through music
	Entertainment through excursions
	Lack of stimulation
Reflection	Inclined to reflection
Satisfaction of reflection	Intellectual satisfaction
	Displeased with superficial conversations
	Entertainment is trivial
Concern for others	Desire to care for the family
	Showing hospitality
	Desire to help others
	Desire to reciprocate
	Contributing to the common good
Satisfaction of concern for others	Feeling of being needed
	Serving a higher purpose
	Feeling of being useless
	Feeling unable to reciprocate
Self-centredness	Rejecting social commitments
	Putting oneself and one’s needs first
	Struggle between duty and self-concern
	Reduced selfishness
Satisfaction of self-centredness	Satisfying self-interest
	Self-neglect

(continued)

Table 5.5 (continued)

Self-presentation	Creating a positive impression by dressing and grooming
	Leaving a positive impression on staff
	To be in the focus of attention
	Desire to be respected
Satisfaction of self-presentation	Feeling comfortable with attractive appearance
	Being appreciated by others
	Being respected as a person
	Afraid of co-stigmatization
	Not being respected as a person
	Being completely ignored as a person
Self-concealment	Protection of the intimate sphere
	Desire to remain unnoticed
Satisfaction of self-concealment	Content to remain unnoticed
	Being exposed to the criticism from others
	Being exposed to the gossip of others
	Feeling permanently exposed to public
Positive self-perception	Focussing on the past
	Looking at present achievements
	Downward comparisons
	Trying to feel superior to others
	Forgetting the unpleasant self
Satisfaction of positive self-perception	Positive memories
	Recognizing remaining strength
	Negative image of present self
	Plagued by negative memories
Critical self-perception	Making efforts
	Lowering expectations
Satisfaction of critical self-perception	Acceptance of ageing
	Loss of self-recognition
Influencing factors	
Physical condition	*Same as in Table 5.4*
Circumstances of life	*Same as in Table 5.4*
Environmental factors	Access to nature
	Gift shop
	Shared TV
	Female dominance

Table 5.5 (continued)

Identity-related care	Getting acquainted with residents
	Showing empathy and respect
	Active listening
	Stimulating memories
	Dignity therapy
	Strength spotting
	Story sharing
	Assistance in self-presentation
	Tactful dealing with mishaps
	Creating a protective environment
	Allocation of tasks
	Encouraging residents to continue preferred activities
	Simulating real life situations
	Organizing joint activities Gender specific activities
	No concrete idea about likes and dislikes
	Sessions detached from the lifeworld
	Preventing residents from helping
	Lack of respectful treatment
	Discrimination
	Privileged treatment of higher status residents
Behavioural and attitudinal reactions	Individual activities
	Participation in joint activities
	Social engagement
	Cultivating memories

et al. 2011; Chuang et al. 2015; Shaw et al. 2016; Slettebo et al. 2016). Depending on their interests and abilities, as well as the opportunities of the facility, residents tried to keep themselves busy by drawing, writing, doing woodwork, gardening, solving crosswords or puzzles. Some of these activities were solitary and residents performed them according to their own abilities. Group activities, however, were tailored to the average level of interests and abilities and residents had to adapt to this level. Some residents had a *desire for mental challenge*, and they felt bored if tasks were not demanding (Thomas et al. 2013; Minney and Ranzijn 2016). For example, they lost interest in preparing a certain food if they were only allowed to help with part of the process like mixing or adding ingredients. Others, however, disliked too much challenge and preferred to participate in rather *easy activities that matched their abilities* (Murphy et al. 2007; Cooney et al. 2009).

5.4.1.2 Satisfaction of Work

Residents, who were allowed to assume tasks in the facility or found opportunities for productive leisure activities, *enjoyed being active* (Ball et al. 2004b, Cooney et al. 2009; Cooney 2011; Chuang et al. 2015). Older persons who stayed in assisted living facilities described their satisfaction:

> Every morning I clean the bathroom; I pick up any towels; I pour Lysol in the tank, in the tub. (Ball et al. 2004b)

> I may chop things, like celery, onions, whatever she [the owner] wants me to do. I like to be busy. I don't like to just sit and watch TV. (ibid.)

Others, however, were prevented from performing such activities, because staff said that such tasks were only for workers. As a consequence, they *had nothing to do* and to fill their time (Fiveash 1998; Ball et al. 2000, 2004b; Andersson et al. 2007; Coughlan and Ward 2007; Murphy et al. 2007; Stathi and Simey 2007; Tsai and Tsai 2008; Chuang and Abbey 2009; Timonen and O'Dwyer 2009; Cooney 2011; Chang 2013; Martinsson et al. 2013; Nakrem et al. 2013; Hillcoat-Nalletamby 2014; Gustavsson et al. 2015; Bollig et al. 2016; Palacios-Ceña et al. 2016a; Slettebo et al. 2016; Mohammadinia et al. 2017; Koppitz et al. 2017). Being condemned to inactivity, they could not use and exhaust their mental energy. All they could do was take care of themselves or do nothing.

> I get so tired of not doing anything […] four hours just trying to get myself clean and cutting my fingernails and rolling my hair and just things like that. (Ball et al. 2004b)

> When I was in my home and busy 24 h, I didn't have time for anything, and now. I don't know what to do, time eats me (Palacios-Ceña et al. 2016a)

The same occurred if facilities provided no opportunities for productive leisure activities. One resident, for example, complained that a sewing room had been closed.

> This offer does not exist anymore. They cannot afford it anymore. It has been removed from all nursing homes: there is nothing. We just sit in the chair … that is what we do. (Bollig et al. 2016)

If residents had no opportunity to be productive in one way or another they felt that they *had achieved nothing.*

> One does not have the feeling of having accomplished work and deserving sleep. (Herrmann and Flick 2011)

5.4.1.3 Relaxation

Not everybody, however, complained about inactivity. To some extent, residents also had a *desire for idleness* (Andersson et al. 2007; Williams and Warren 2008;

Raske 2010; Schenk et al. 2013; Behr et al. 2014; Slettebo et al. 2016). Being released from the duties of independent life, they wanted to relax, to "take it easy" at times, and not always having to be "doing something" (Schenk et al. 2013). As a consequence they could reject the participation in joint activities that were meant to keep them busy. Some even said that they had become phlegmatic (Behr et al. 2014). Such disinterest in activity may, of course, result in boredom and lack of stimulation. To some extent, however, *calming down the mind* was a counterbalance for mental engagement and residents considered it to be a useful way of reducing inner stress and promoting sleep and recovery. Some residents even used purposeful strategies to achieve this goal.

> One can calm down by reading or a conversation in the evening. One should try to have nothing exciting. […] You know what I mean. Exciting or appealing books or reading material of this type or that type. One should instead take something calm or gentle. (Herrmann and Flick 2011)

5.4.1.4 Satisfaction of Relaxation

By sitting there and doing nothing, the residents found *rest and relaxation* (Raske 2010; Herrmann and Flick 2011; Schenk et al. 2013; Behr et al. 2014; Slettebo et al. 2016).

> During the weekdays, nothing happens. I only sit here looking out the windows. But I like to do this. (Slettebo et al. 2016)

According to them, a well dosed phlegmatism showed a positive effect on the mind

> Well, that I can relax. You know? That nothing bothers me, that nothing is on my mind. You know? (Herrmann and Flick 2011)

This recreational effect could be increased by a quiet, natural environment. It was promoted by easy access to outdoor areas with fresh air and sun, and residents told about their *enjoyment of nature*—especially when the facility had a garden (Tsai and Tsai 2008; Raske 2010; Nakrem et al. 2013; James et al. 2014).

> To me, the most luxurious thing that I can do is to be wheeled into the sunshine outside. (Tsai and Tsai 2008)

Sometimes, however, residents could not fulfil their desire for mental relaxation because joint activities were too strenuous in relation to their abilities or because they had too many of them. As a consequence, they *felt overburdened* (Koch-Straube 2003; Williams and Warren 2008; Thomas et al. 2013; James et al. 2014; Minney and Ranzijn 2016). Some residents also said that their minds were so busy that they were *unable to relax because of their rumination.*

> And I don't fall asleep. That is the problem. Then it's that one thinks about some things and ruminates about some things. However, I guess there is nothing to do about it. (Herrmann and Flick 2011)

5.4.2 Diversion Versus Reflection

5.4.2.1 Diversion

Work and productive leisure activities kept residents busy and relaxation allowed them to recover. Both, however, could also become monotonous and had to be supplemented by some kind of diversion that stimulated the mind of the residents. Until retirement, the desire for productive work and the desire for diversion were met separately in either work or leisure time. After retirement older persons maintained this distinction because they perceived some activities as duties and others as pleasure. Furthermore, the absence of labour constraints enabled them to realize their desire for productive work more freely and independently. As residents in long-term care facilities, however, they were often deprived of the opportunity to work—either due to lack of physical abilities or due to institutional regulations. Hence, participation in activities that were rather meant for their diversion became a substitute for activities they had performed to satisfy their desire for productive labour. As a consequence, the difference between diversion and work became blurred. Some joint activities like handicrafts were meant to meet both needs simultaneously, whereas others like parlour games were mainly of an entertaining character, and since they kept the residents busy, they became a substitute for work.

Under these conditions, many residents expressed a *desire for collective amusement* (Josat 2005; Bergland and Kirkevold 2006; Murphy et al. 2007; Hjaltadóttir and Gustafsdóttir 2007; Harmer and Orrell 2008; Bowers et al. 2009; Cooney et al. 2009; Hutchinson et al. 2011; Falk et al. 2013; Schenk et al. 2013; James et al. 2014; Slettebo et al. 2016). They wanted to be entertained by activities according to their taste.

> My best hobby of all is playing cards, I play four times a week with four other ladies. (Cooney et al. 2009)

Parlour games like playing cards or bingo were a welcome means to find entertainment. Excursions were another source of diversion, but also simple get-togethers and drinking coffee. Some residents, in fact, did not want anything else but to have a conversation in order to meet their need for diversion (Andersson et al. 2007; Nakrem et al. 2013). Others had a *desire for an increased stimulation* (Bergland and Kirkevold 2006; Harmer and Orrell 2008). They preferred events with dance or singing.

> Singing, for example that's important, that's, yes, and what else is it they do, oh we do gymnastics and, goodness, all sorts and memory training that's really important too… And above all for the folks who can't walk anymore, so that they're looked after too and that they get out and aren't just sitting in their rooms all the time. (Schenk et al. 2013)

There were also those who mentioned a *desire for individual entertainment* that they satisfied by listening to the radio or watching TV (Hutchinson et al. 2011; Hwang et al. 2013; Nakrem et al. 2013; Slettebo et al. 2016).

5.4.2.2 Satisfaction of Diversion

The desire for diversion was met when residents found *pleasure in social activities*. Mealtimes provided entertainment through conversation with tablemates (Grau et al. 1995; Wu and Barker 2008; Chuang and Abbey 2009; Curle and Keller 2010; Philpin et al. 2011; Chuang et al. 2015; Bollig et al. 2016). They were the social event of the day, and residents perceived it to be its highlight—in part due to a lack of other distractions. Joint activities organized by staff provided additional pleasure. Especially bingo and other parlour games were a source of delight (Cooney et al. 2009; Slettebo et al. 2016). Occasionally, residents even made jokes and were hilarious (Koch-Straube 2003). A café inside the facility was another source of distraction (Andrew and Wilson 2014). Some residents told how they experienced *joy through music* (Harmer and Orrell 2008; Nakrem et al. 2013; Adra et al. 2015; Slettebo et al. 2016). Singing together could even show an effect on their physical well-being:

> All the music's going through your head with it and it makes you more appetizing. (Harmer and Orrell 2008)

Some residents were also fond of dancing. They were, however, not able to share their pleasure with their roommates as it required physical abilities. So they had to attend events outside the facility and needed transportation for this purpose (Slettebo et al. 2016). One way of making this pleasure available to residents with physical disabilities was to offer sit dance (Nakrem et al. 2013). Since residents spent most of their time indoors and always saw the same environment they also enjoyed an *entertainment through excursions* (Hjaltadóttir and Gustafsdóttir 2007; Park et al. 2009; Falk et al. 2013; Thomas et al. 2013; Minney and Ranzijn 2016).

> Oh, I just love when they (nursing staff) wake me up in the morning and I know that today is the day we're going for a trip to Denmark, or have a day in the country. (Falk et al. 2013)

If no excursion was possible, they wanted to spend at least some time outside the facility to get distracted (Hwang et al. 2013). Quite often, however, their desire for diversion remained unsatisfied and the residents complained about a *lack of stimulation* (Fiveash 1998; Hweidi 1999; Hjaltadóttir and Gustafsdóttir 2007; Murphy et al. 2007; Chuang and Abbey 2009; Cooney et al. 2009; Timonen and O'Dwyer 2009; Cooney 2011; Park et al. 2012; Chang 2013; Thomas et al. 2013; James et al. 2014; Nakrem 2015; Mohammadinia et al. 2017). The daily routine was monotonous and repetitive and the institution-like atmosphere at the nursing home was depressing and stifling.

> …just the same thing, the same day in and day out…it's boring. (Cooney et al. 2009)

On the long run, even means of entertainment turned out to be insufficient.

> We're sitting down all day doing nothing in the unit. Sitting on the bed, looking at television. I'd like something else. It drives me nuts at times. (Timonen and O'Dwyer 2009)

> Although the place has a green and pretty courtyard, our days are so repetitive and monotonous and this green space is of no avail to us. Even some days I do not like to come here and see the yard. (Mohammadinia et al. 2017)

5.4.2.3 Reflection

To some extent, diversion needed to be counterbalanced by reflection, so that residents did not get tired of it. There were also those who were generally more *inclined to reflection* and disliked the entertainment through joint activities.

> I feel better walking and reflecting than dancing or singing. Nothing is wrong with me, but they don't stop telling me that I must socialize in order to improve my quality of life. (Palacios-Ceña et al. 2016a)

These residents often preferred solitary activities like thinking or reading.

> I am very fond of reading. I have always read a lot. So it is actually reading that keeps me going. I have a lot of books myself. (Slettebo et al. 2016)

Some of them, however, also liked to join together and tried to form a study circle where they could discuss their reading (Hutchinson et al. 2011; James et al. 2014).

5.4.2.4 Satisfaction of Reflection

Those who were able to read and discuss derived *intellectual satisfaction* from these activities (Shaw et al. 2016; Slettebo et al. 2016).

> All of my books that I'd never read. When I moved here, I read all of them. (Shaw et al. 2016)

The topics for intellectual engagement did not have to be complicated. It was enough to gain new insights. One resident, for example, described how he experienced the talks that a staff member gave in the afternoon.

> … these talks in the afternoons, which I've found very informative […] the talks are aimed at us 80 years plus, puts me in context, gives me an understanding of what other people are talking about. I want a better understanding of what goes on […] It was fascinating really. […] Knowledge is what makes you more comfortable, knowing what the hell is going on (Shaw et al. 2016)

Quite often, however, social events were less satisfying for residents with an intellectual inclination. They were *displeased with the superficial conversations* of their roommates (Koch-Straube 2003; Roberts and Bowers 2015):

> They […] have the same things in mind. Flowers and grass and … And I don't like that […] I never did. I never went to uh, the neighbours with coffee klatches. (Roberts and Bowers 2015)

They were also tired of joint activities as they perceived this kind of *entertainment to be trivial* or “babyish” (Ball et al. 2000; Tucket 2007; Dobbs et al. 2008; Chang 2013; Sandhu et al. 2013; Stevens et al. 2015; Christov 2016; Palacios-Ceña et al. 2016a; Koppitz et al. 2017)

> Every program consists of sitting around and talking about the old days, not discussion. Sometimes it really gets on my nerves, yes… Is it interesting for the elderly? They are ridiculous… (Chang 2013)

> Most of the activities are very childish, like those nursery rhymes. (Sandhu et al. 2013)

> …I don’t like it — they have musical thing… Like sing old songs and they make you miserable… But I think they are trained to do it… It’s a ‘Long Way to Tipperary’ — if I hear that again I’ll *scream* ….Yes. I tell them that (these songs upset me) and *they* laugh. They say others love them. (Tucket 2007)

5.4.3 Concern for Others Versus Self-Centredness

Although residents in long-term care facilities had limited abilities and facility staff took care of them, they were not only driven by self-interest. They still had a concern for others. This concern was not motivated by an adjustment to social standards. It was rather a spontaneous feeling regarding other persons to whom they felt attached.

5.4.3.1 Concern for Others

Although they lived away from their children, residents in long-term care facilities still had a *desire to care for their family*. As parents they were concerned about the well-being of their offspring:

> My Irene’s a good daughter and she’s got a good husband so I feel content. When they’re happy, I’m happy. (Minney and Ranzijn 2016)

As grandparents they wanted to give presents to their grandchildren or—if they were able to do so—to produce something for them. One female resident, for example, was busy with knitting socks for them (Nakrem et al. 2013). If they had assets, they liked to distribute their money and possessions to their offspring (Melin-Johansson et al. 2014). The minimum they wanted to do for their visiting friends and relatives was to *show them hospitality*—for example, by inviting them to cake and coffee (Andrew and Wilson 2014).

The residents also had a *desire to help others* (Bowers et al. 2001; Iwasiw et al. 2003; Ball et al. 2004b; Kennedy et al. 2005; Robichaud et al. 2006; Harmer and Orrell 2008; Williams and Warren 2009; Kemp et al. 2012; Park et al. 2012; Sandhu et al. 2013; Schenk et al. 2013; Hillcoat-Nalletamby 2014; Adra et al. 2015; Minney and Ranzijn 2016), for example, by caring about newcomers (Robichaud et al. 2006; Iwasiw et al. 2003) or by supporting roommates with dementia in meeting their individual needs (Minney and Ranzijn 2016).

> In my eyes, quality of life is when you do something, something meaningful, especially when you can make others happy, that's, that's the meaning of life after all, when you do some- especially do something that makes you happy and that can also make others happy. (Schenk et al. 2013).

> I worry about [my neighbour] and I'll mention something to [the staff] if I think it needs [their] attention. I have nothing in common with her other than I worry about her. (Kemp et al. 2012)

Contributing to the social life in the facility according to their individual abilities, for example, by playing music, was another way to show concern for the community.

> I play the piano because nobody else seems ready to play round here. I'm not wonderful at it but I play and enjoy it. And some of the older folk ask for certain songs … and I know that, so it gives me pleasure to think I'm helping them. (Hillcoat-Nalletamby 2014)

Others wanted to perform housekeeping roles knowing that their work was for the benefit of their roommates (Ball et al. 2004b). Concern for others was important to the residents, because they did not want to be selfish and to receive only favours from them. They had instead a *desire to reciprocate* (Bowers et al. 2001; Ball et al. 2004b; Robichaud et al. 2006; Wu and Barker 2008; Heliker 2009; Jordan 2010; Chang 2013; Oosterveld-Vlug et al. 2014; Lung and Liu 2016). This concerned mainly their caregivers who provided the support they needed. Residents tried to reciprocate by giving them small presents, by comforting them when they were in sorrow, and by helping them in order to reduce their workload.

> Sometimes my friends come and visit me with fruit or biscuits, etc., and I would give the nursing assistants some. (Lung and Liu 2016)

> A nursing assistant didn't feel well, I attempted to comfort her… and I would also ask her if she was feeling better the next day.… We know, you care about me, and so do I (ibid.)

> They do so much and work so hard. I try to find little ways to take some of the burden off. (Bowers et al. 2001)

Residents in a facility for the poor in Ethiopia who could hardly provide for themselves wanted at least to *contribute to the common good*—even if this contribution consisted only of praying.

> Our aim is to serve the Ethiopian people and our country through praying and to be blessed. (Teka and Adamek 2014)

5.4.3.2 Satisfaction of Concern for Others

Satisfying their desire to show concern for others gave the residents a *feeling of being needed*. Helping others by encouraging or providing practical support gave them a sense of purpose in life (Dobbs et al. 2008; Timonen and O'Dwyer 2009; Kemp et al. 2012; Park et al. 2012; Perkins et al. 2012; Park et al. 2013; Behr et al. 2014; Hillcoat-Nalletamby 2014; Slettebo et al. 2016).

> My activities are very limited. Now I will try to—the best I can—assist other people here. […] You know, it makes me feel useful! It gives me a sense of well-being, that I'm helping my neighbour. (Park et al. 2012)

> If I can help somebody as I pass along, if I can cheer somebody with a word or song, if I show somebody he is shrouded in wrong, then my living shall not be in vain. (Park et al. 2013)

Helping in the facility by contributing to the work that had to be done had the same effect. (Ball et al. 2000, 2004b; Williams and Warren 2008; Cooney et al. 2009; Perkins et al. 2012; Minney and Ranzijn 2016)

> Yesterday we were short of staff and I was in the kitchen and I was a carer, you know, I did everything. They all said, 'oh, you did work so hard!' I felt needed, do you know what I mean? It felt like the old times and that was really good (Minney and Ranzijn 2016)

The above-mentioned residents in Ethiopia felt that by praying for the welfare of their country they *served a higher purpose* they had been chosen for.

> Our purpose is not enjoyment. To pray and to live in the will of God is our main leisure activity that makes us happy. (Teka and Adamek 2014)

> Most of us were wounded with our past life. I think when God has chosen you for a special purpose he did everything you do not like it. Finally I am here to pray and to be happy. God will not leave you idle. (ibid.)

Other residents, however, did not find that they could contribute to the lives of others and expressed their *feeling of being useless*. Some of them had this feeling due to the way they were treated by the society:

> You notice that when you get old, people stop taking you seriously: 'That person's so old, we'll just park him in a corner then he won't bother us any more'. That's often what happens…. Yes, you no longer count, you know. (Oosterveld-Vlug et al. 2014)

Others felt that their frailty prevented them from contributing to the society as they desired (Shin 2008; Heliker 2009; James et al. 2014). Their existence was reduced to a satisfaction of their own needs and this forced self-centredness gave them the feeling of having no purpose in life. If they were only able to receive care from others they *felt unable to reciprocate*. They could do them no favours in return. Koch-Straube (2003) notes that it was common in German nursing homes for residents not to have their own money and therefore not to receive bills. Being unable to pay for the services they received they had no visual proof that they gave something in return.

5.4.3.3 Self-Centredness

To some extent, residents also told about their self-centredness which was a necessary counterbalance to their concern for others. Most of them, however, did not go into detail because self-concern is a natural part of life and inherent in most activities without people thinking about it. Furthermore, self-interest is often at the expense of others and is therefore not socially desirable. Residents with such an exaggerated self-interest were not likely to talk about it in interviews, but their self-centredness became apparent in their behaviour as it was experienced by their caregivers and as it could be observed by researchers in observational studies. For example, the expectation to be in command and to control care, which was for some residents a central motive of their social orientations of action, was also a clear sign of self-centredness. It was motivated by the desire to satisfy their own needs at will—at the expense of their caregivers, whom they expected to comply with their wishes, and at the expense of their roommates, who were expected to wait for these caregivers until their own needs had been satisfied.

In some interviews, selfishness became apparent when the residents *rejected social commitments*. One older woman told, for example, why she gave up caring for others:

> When I think about what I would never do again - this is - to work for the Red Cross again - I saw too much blood over there - now I just think about myself. (Whispering) You can kiss my ass. (Christov 2016)

Others admitted that they were still self-centred and *put themselves and their needs first* (Melin-Johansson et al. 2014). As they told, their focus had always been on the well-being of their family. They had had no time to think about themselves, because there was always someone else who needed their attention and took priority. Being released from their duties they now wanted to get some compensation. Others still had a care dependent spouse, and moving into a long-term care facility offered them the chance to take care about their own needs because professional support relieved them from parts of their duties. At the same time, however, they still felt indebted to the marital obligation and experienced a *struggle between their duty and their self-concern* (Shaw et al. 2016). Whereas these older persons learned to increase their self-interest, others were on the way to unlearn it and they told about their *reduced selfishness*. As they said, they became less interested in material possessions and it was easy for them to give away their assets for the benefit of others.

> I'm not that interested in money, but I think it is nice to give it away to my grandchildren and children. (Melin-Johansson et al. 2014)

5.4.3.4 Satisfaction of Self-Centredness

To some extent, residents were able to *satisfy their self-interests*. This was the case when caregivers obeyed and complied with their wishes or when roommates gave them the attention they desired when they tried to dominate the conversation. However, as we saw in the previous section, such desires remained quite often unmet because they had to subordinate to their caregivers or to wait until they received the help they required. An exaggerated concern for others could also prevent the satisfaction of their own needs, as it was the case when a resident had to take care of a spouse. Due to a feeling of marital duty their concern for the needs of the other led to *self-neglect* (Melin-Johansson et al. 2014; Shaw et al. 2016). Women, in particular, were prone to such self-neglect as they had been taught to take care more for others than for themselves.

> No, I've never experienced myself as important, not now or in the past. Other people have always been more important – parents, employer, my husband, my daughter – I was never important. I never thought of myself. (Melin-Johansson et al. 2014)

5.4.4 Self-Presentation Versus Self-Concealment

Although residents in long-term care facilities were largely excluded from social participation they still wanted to get the attention of others and to be respected as a person. For this reason, they were interested in their self-presentation. Since any self-presentation may attract too much or even unwanted attention, residents were also inclined to conceal themselves at least to some extent. Self-concealment was, in fact, a necessary counterbalance to achieve a respectable self-presentation.

5.4.4.1 Self-Presentation

The tendency to attract the attention of others could be observed at mealtimes where residents wanted to *create a positive impression by dressing and grooming* (Dobbs 2004; Murphy et al. 2007; Cooney et al. 2009; Nakrem et al. 2011; Bauer et al. 2013; Falk et al. 2013; Melin-Johansson et al. 2014; Oosterveld-Vlug et al. 2014, Naess et al. 2016). They prepared themselves for social gatherings and tried to hide aspects of their bodies that could be perceived as negative by others.

> I would still really like to look good and I want to smell nice, that kind of thing. I think that does have to do with dignity, so that they don't come up to you and think 'Oh, she stinks,' and so on. I would hate that (Oosterveld-Vlug et al. 2014).

This self-presentation was in accordance with social norms, but it also implied a desire for some social distinction. As Dobbs (2004) observed at mealtimes in assisted living, there seemed to be at times a competition of dressing better than anyone else in the setting. By "dressing up" for the public eye the women tried to show their beauty. Another way to attract the attention of others was to demonstrate one's capabilities. In this sense, some residents made efforts to *leave a positive impression on the staff* and were eager to get the recognition of their caregivers.

> It feels good to be appreciated by the staff, when they see that, I can still do something (James et al. 2014)

An exaggerated desire to get attention was sometimes observed at mealtimes or at social gatherings where some residents wanted *to be in the focus of attention*. Curle and Keller (2010) observed how such residents tried to dominate social interactions and described them as "dominant leaders who impeded interactions as they did not encourage positive responses from others, spoke primarily about their own interests and issues, and maintained little attentive behaviour. Sometimes dominant leaders existed in pairs and would control table conversation by excluding or rebuffing other tablemates from their conversation, providing little opportunity for others to interact verbally" (Curle and Keller 2010).

But also those who were less eager to attract the attention of their social environment had the *desire to be respected* (Bergland and Kirkevold 2006; Robichaud et al. 2006; Andersson et al. 2007; Schenk et al. 2013; Oosterveld-Vlug et al. 2014; Teka and Adamek 2014; Chuang et al. 2015; Bollig et al. 2016; Naess et al. 2016). This expectation concerned the treatment they wanted to receive from their caregivers:

> They need to be polite to older persons. More polite. Respect us. (Chuang et al. 2015)

> Actually, greeting is not a big deal, but the feeling is good. (ibid.)

Or, as the residents of the Ethiopian facility for poor older persons put it:

> We prefer greeting rather than eating (Teka and Adamek 2014)

Such treatment was a question of dignity that had to be bestowed on them as persons, irrespective of whether they made efforts to attract the attention of others or not.

5.4.4.2 Satisfaction of Self-Presentation

To some extent, residents were able to present themselves and to satisfy their desire for attention. Women who dressed up nicely at mealtimes apparently *felt comfortable with their attractive appearance*, which allowed for some social distinction (Falk et al. 2013).

In some cases, activities to meet the desire for work or for diversion could result in the *appreciation by others*. Some residents, for example, explained that singing was not only a source of individual joy, it also gave them a feeling of being seen and heard as an important member in the social life of the nursing home (Slettebo et al. 2016). Another resident told how her passion for cooking earned her the recognition of the other residents:

> They like my tossed salad. They call it 'Mamie's salad'. (Ball et al. 2004b)

The desire for respect—irrespective of attempts to attract the attention of others—was met when the residents were *respected as persons* and treated as acceptable members of the community (Hjaltadóttir and Gustafsdóttir 2007; Harmer and Orrell 2008; Cooney et al. 2009; Wu et al. 2009: Cooney 2011; Falk et al. 2013; Goddard et al. 2013; Hwang et al. 2013; Oosterveld-Vlug et al. 2014; Lung and Liu 2016). Such recognition was granted when caregivers treated them in a respectful way, respected their privacy, paid attention to their wishes, showed interest in their lives, and gave them tasks that allowed residents to contribute to life in the facility. What was experienced as respectful treatment depended on the social status of the resident and on cultural manners.

> Nurse X is very good. Every time she sees me, she always calls me 'grandma'. It is enough. I am very happy. It makes me feel more comfortable to live here… (Wu et al. 2009)

> I really love to hear the nursing assistant calling me 'teacher'… because I was a teacher for my whole career. […] Because at least they know I was a teacher, not someone ordinary, but an intellectual…. The way they call me that, it feels like they are showing respect. (Lung and Liu 2016)

> They usually call me 'big sister' and I call them 'little sister.'… I feel happy we call each other 'sister' … it seems that they all familiar with me and treat me well. (ibid.)

Cultural habits also determined how the residents were called. In some countries it was customary to use the first name, in others the surname was preferred.

> All the nurses on this floor know me by my-by my first name. Of course, they always address me by mister, but they all know me. Yes indeed. So, I know that they have a personal interest in the individual. (Jordan 2010)

Quite often, however, the desire to get attention from others and to receive their respect was not satisfied. For some residents, the mere fact of living in a long-term care facility was a threat to being perceived as a respectable member of society. Living together with disabled persons made them fear of getting a bad reputation and they were *afraid of co-stigmatization* (Dobbs et al. 2008; Christov 2016). Staff members, for example, observed how some residents did not like to go on outings because they did not want to be seen with other residents using wheelchairs (Dobbs et al. 2008).

Apart from this fear of losing one's social reputation, there was also the direct experience of *not being respected as a person* (Grant et al. 1996; Dobbs et al. 2008; Timonen and O'Dwyer 2009; Williams and Warren 2009; Falk et al. 2013; Chuang et al. 2015; Teka and Adamek 2014; Stevens et al. 2015; Donnelly and MacEntee 2016; Rahayu et al. 2018). Residents complained about a lack of esteem and a disrespectful treatment, which manifested itself in ageism and infantilizing and sometimes even rude behaviours by others.

> It's like they think we're children…at least they give the attitude. So I think they should recognize people here are elderly but they aren't stupid and they aren't three years old (Williams and Warren 2009)

> The diminutives! The endearments! The idiotic we's. Hello dear, how are we today? What's your name dear? Shall we go to the dining room Eve? Hi hon… Don't we look nice today!… Chirpy singsong voices. Who thinks we want to be talked to this way? (ibid.)

> When care giver growled at me, I felt hurt, I wanted to weep… (Rahayu et al. 2018)

Others did not complain about such apparent disrespect, they rather told how they were *completely ignored as a person* (Iwasiw et al. 1996; Heliker and Scholler-Jaquish 2006; Hellström and Sarvimäki 2007a, b; Westin and Danielson 2007; Cooney 2011). They felt that they were just a mere number to others, while their true self remained unknown to them.

> They don't know the meaning of me! They don't know the meaning of me. (Heliker and Scholler-Jaquish 2006)

5.4.4.3 Self-Concealment

The desire to attract attention was counterbalanced by a tendency to self-concealment. Self-concealment was ensured by maintaining privacy which kept others, who were rather strangers, out of one's own affairs and *protected the intimate sphere* (Iwasiw et al., 2003; Bergland and Kirkevold 2006; Hjaltadóttir and Gustafsdóttir 2007; Murphy et al., 2007; Hauge and Heggen 2008; Shin 2008; Chin and Quine 2012; Falk et al. 2013; Schenk et al. 2013; Nakrem et al. 2013; Chuang et al. 2015; Bollig et al. 2016).

> I've made a system of not letting anyone in my room. I don't want unfamiliar people running around in here, and I want to feel that this is mine and that I can do whatever I want in here. (Falk et al. 2013)

> To go to the toilet at night, that, I think, is very inappropriate here. Imagine if I could have a little toilet that was only mine (Bergland and Kirkevold 2006)

Self-concealment was also apparent in a *desire to remain unnoticed* (Curle and Keller 2010; Christov 2016) as it was observed by some researchers. While some residents tried to be in the focus of attention and dominated discussions at mealtimes, most residents were just silent spectators of such self-presentations (Curle and Keller 2010). Christov (2016), who investigated the question why residents in many nursing homes remain silent, observed that they behaved with caution when they participated in joint activities since some group members liked to reprimand others for what they considered to be inappropriate behaviour. Since older people could not avoid the attention of others while in the public sphere, they tried to be as inconspicuous as possible to hide aspects of their personality that could contribute to an unpleasant self-portrayal in the eyes of others.

5.4.4.4 Satisfaction of Self-Concealment

If residents could retreat and were not exposed to the criticism of their roommates, they were *content to remain unnoticed*. There were, however, situations when they could not avoid the attention of others. Christov (2016) describes how they were *exposed to the criticism of others* when they participated in joint activities—even if they behaved with caution and tried to be inconspicuous. In case of mishap, other group members made their comments and sometimes it even provoked criticism if they remained silent. There were also occasions when residents were *exposed to gossip*. Christov (2016), for example, describes an incident in which a resident who returned from her husband's grave was degraded to an object of conversation by her roommates who talked about her while she was present and made even jokes about her situation. Likewise situations that made older persons feel ashamed like having to undress in front of a caregiver violated their desire for self-concealment. Their inability to adapt to social standards gave them at the same time the feeling of being an object of curiosity that one could dispose of without showing any sign of respect.

Similar feeling arose when others invaded the privacy of the residents. This was the case when they were monitored by staff, especially during night checks, or when other residents entered their private rooms without permission. For residents who lived in single rooms, such incidences were an occasional nuisance. Those, however, who stayed in shared rooms had no chance to withdraw and *felt permanently exposed to the public* (Iwasiw et al., 1996; Fiveash, 1998; Bland, 2007; Murphy et al., 2007; Chuang and Abbey, 2009; Cooney et al., 2009; Fraher and Coffey, 2011; Hutchinson et al., 2011; Chin and Quine, 2012; Oosterveld-Vlug et al., 2014). As one of them put it:

> The biggest thing that worries me is the lack of privacy… your life is like an open book. (Iwasiw et al. 1996)

The same was true for residents who were wheelchair-bound and had been left in the common room by their caregivers so that they were forced to spend their whole day there (Hauge and Heggen 2008; Koch-Straube 2003). In some facilities, residents had to live in large open plan wards and they hardly had a chance to conceal themselves, as there were only curtains around their beds that visually protected them from the eyes of others, and they knew that even when the curtains were closed, everyone knew what was going on (Cooney et al. 2009).

5.4.5 Positive Self-Perception Versus Critical Self-Perception

Residents did not only strive for a balance between attracting attention and self-concealment, they also had to gain a balanced self-awareness that allowed them accepting both their strengths and weaknesses. The awareness of their strengths could give them an embellished self-image, while the awareness of their weaknesses was a necessary counterbalance that enabled them to obtain a realistic idea of themselves. To some extent, older persons gained a positive self-image when they got attention and acknowledgement from others. On the other hand, lack of acknowledgement made older persons aware of their reduced abilities and diminished their self-esteem. Their self-perception, however, was not completely determined by the feedback of their social environment. An awareness of own strengths could boost their self-consciousness even if they were not acknowledged by others.

5.4.5.1 Positive Self-Perception

Naturally, older persons were more inclined to perceive their strengths. To obtain a positive self-image they used strategies of selective self-awareness. Some *focused on the past* and tried to remember their accomplishments (Koch-Straube 2003; Hjaltadóttir and Gustafsdóttir 2007; Melin-Johansson et al. 2014; Oosterveld-Vlug et al. 2014). Others *looked at their present achievements*. Instead of mourning their lost abilities, they prided themselves on what they could still do or what they had regained after recovering from an illness (Oosterveld-Vlug et al. 2013a: Adra et al. 2015). Another way of obtaining self-acceptance was to compare oneself with others who were worse of. Such *downward comparisons* could boost the self-esteem of the residents (Oosterveld-Vlug et al. 2013a; Nakrem et al. 2013; Behr et al. 2014; Oosterveld-Vlug et al.2014; Christov 2016). Some residents *tried to feel superior to others* by devaluating their roommates, for example, by criticizing them or commenting their behaviour while they were present (Koch-Straube 2003; Christov 2016). It also occurred in the form of gossip about other residents when they were absent and it could result in the above-mentioned exclusion of others. Confronted with their physical decay, some residents completely withdrew in memories in order to *forget their unpleasant self*. Koch-Straube (2003) assumes this to be a reaction to protect the natural sense of self-worth.

5.4.5.2 Satisfaction of Positive Self-perception

Despite their losses and their physical decline, some residents were able to maintain their self-esteem by dwelling on *positive memories* (Hjaltadóttir and Gustafsdóttir 2007; Hutchinson et al. 2011; Goddard et al. 2013; Melin-Johansson et al. 2014; Oosterveld-Vlug et al. 2014; Iden et al. 2015).

> Well, I've always been successful, I've had to build up everything myself. I never had any friends giving me a leg-up, so yes, I don't owe anyone anything fortunately. (Oosterveld-Vlug et al. 2014)

Having something accomplished in life was of course a prerequisite for positive memories. What was perceived as an accomplishment, however, depended on everybody's own value system. It could just be the fact of having lived a long life.

> Being 97 (age), oh I think it kind of makes you feel good; in general (people) kind of honour you for that. (Hutchinson et al. 2011)

Residents could also gain a positive self-image by focusing on the present and *recognizing their remaining strength* (Oosterveld-Vlug et al. 2013a; Adra et al. 2015). Some of them told about their satisfaction of being still able to participate in age appropriate exercises, while others were glad about a successful recovery from a disease:

> Well, it [sense of dignity] was worse then [six months ago]. Yes, much worse. Yes, well not any more - you get your feeling of dignity back after a bit, don't you? Because now I go home on my own in the minibus. And then I go upstairs on my own, along the access balcony, I go back down, get the minibus at seven o'clock, it's all those little things that I'm able to do again. Yes, I've been able to get a little bit of grip back on my life again. (Oosterveld-Vlug et al. 2013a)

More often, however, residents told of a *negative image of their present self* (Fiveash 1998; Ball et al. 2004b; Coughlan and Ward 2007; Saunders and Heliker 2008: Nakrem et al. 2011; Bauer et al. 2013; Falk et al. 2013; Oosterveld-Vlug et al. 2014; Iden et al. 2015; Shaw et al. 2016; Cho et al. 2017). They compared themselves to the person they once were, and with the loss of their abilities and strengths and the traces of ageing in their appearance they felt incapable and unattractive. One older man felt that he “went from a strong man to a nothing” (Shaw et al. 2016), and a female resident considered herself to be “just a numb nitwit” and added:

> I think. I was smart, but I think I lost it all’cause I just don’t do like I used to. (Ball et al. 2004b)

Being dependent on the help of others was for them a humiliating experience which sometimes caused a complete loss of their self-esteem:

> I don’t feel like a human being because it’s hard for me to move [by myself]. I need others’ help to stand up and [sit] down or go to [the] hospital. Other residents assist me all the time. This is why I say I don’t feel like a human being. (Cho et al. 2017)

Some residents were also unable to resort to positive memories. They were instead *plagued by negative memories*, remembered their mistakes and wrong decisions and felt guilty (Hjaltadóttir and Gustafsdóttir 2007; Melin-Johansson et al. 2014; Minney and Ranzijn 2016; Mohammadinia et al. 2017)

> More often than I wish, I reflect on my past life and things that have been unhappy. Some of the things that I’ve done one way, and wish I’d done another. Yeah, there are a few regrets. (Minney and Ranzijn 2016)

Some even considered the fact that they had to stay in the nursing home as a kind of punishment for bad deeds.

> Why I am here? I do not know; I say maybe I was not a good daughter to my father. (Mohammadinia et al. 2017)

5.4.5.3 Critical Self-Perception

Although such critical self-awareness could result in discouragement and loss of self-esteem, it was to some extent a necessary counterbalance to a one-sided perception of own strengths. It confronted residents with their weaknesses and made them aware of the difference between their desired and their actual condition. In response, some began *to make efforts* (Ball et al. 2004b; Mahrs Träff et al. 2017) to bring their current state closer to their desired state (for example, by exercising in order to improve their functionality). Others, however, were aware of their limitations and *lowered their expectations* (Ball et al. 2004b; Timonen and O’Dwyer 2009; Shaw et al. 2016). As one resident put it:

> You’ve just got to learn to put up with things (Shaw et al. 2016)

And another added:

> I don’t expect too much from the time I have left… . I’ve done pretty good to go as far as I have. (Timonen and O’Dwyer 2009)

5.4.5.4 Satisfaction of Critical Self-Perception

As the last quotation suggests, an adequate degree of self-criticism could result in an *acceptance of ageing*. It gave older persons a realistic sense of themselves that enabled them to become aware of their weaknesses without undue feelings of negativity. One couple told how they adapted to the idea of being old and care dependent like residents in a nursing home:

> My husband said, ‘No.’ He said, ‘It’s all old people.’ I said, ‘You looked in the mirror lately?’ [laughter] I said, ‘What do you think we are?’ Then, all of a sudden, he started realizing, too, that it was getting harder for us. That’s why he said, ‘OK. We’ll move in there.’ (Shin 2015)

In this way, a critical self-perception led to a real self-acceptance which implies both the acceptance of strengths and weaknesses.

Others, however, did not achieve such a self-acceptance. Koch-Straube (2003) observed residents who were unable to recognize themselves when they were shown a photo of themselves. She argues that this *loss of self-recognition* was not simply a sign of mental confusion, but rather a mechanism of self-defence against the awareness of their progressive decay which was a violation of the natural self-love and narcissism. According to her, these residents forgot their current condition and retreated to a world of their own imagination, which allowed them to maintain an illusionary perception of themselves.

5.4.6 Influencing Factors

Just like body-related and social orientations of action, identity-related orientations of action were influenced by physical conditions, circumstances of life, environmental factors, and the care the residents received. Physical impairments resulted in care dependency and a loss or self-reliance which in turn reduced the ability to find satisfaction through work and increased the awareness of one’s own weaknesses. Hearing impairments restricted the participation in joint activities that provided diversion, whereas visual impairments prevented residents from reading which contributed to entertainment or reflection (Thomas et al. 2013). Financial resources and a voluntary entry into the facility did not only strengthen the sense of control, but also facilitated the satisfaction of self-centredness. The absence of such circumstances could have the opposite effect.

5.4.6.1 Environmental Factors

The features of the facility provided a framework for the satisfaction of identity-related needs. An easy *access to nature* fostered mental relaxation (Raske 2010; Cheng et al. 2011; Fraher and Coffey 2011; Nakrem et al. 2013). A garden that belonged to the facility offered a chance to work for those who felt this need and were still able to do so. A *gift shop* as it existed in some facilities provided an opportunity to go shopping and to get some entertainment also for those who could not leave the facility due to impaired mobility (Thomas et al. 2013). In some facilities, however, *shared TV* was the main source of entertainment (Rekawati et al. 2018). Furthermore, all the features of a facility that promoted social contacts, like communal spaces or access to the internet, also contributed to the entertainment and activity of the residents. One factor that negatively affected entertainment for male residents was *female dominance* in the facilities (Park et al. 2009). Since women were in the majority, their interests naturally prevailed and men had to adapt or to avoid joint activities. For example, the passion that women showed for bingo did not arouse much enthusiasm among men. On the other hand, male topics such as world war stories or football did not attract the interest of women.

5.4.6.2 Identity-Related Care

More important than the features of the facility was the attention to the identity-related needs that residents received from the staff. *To get acquainted with the residents* and their individual inclinations was a precondition for person-centred care (Heliker and Scholler-Jaquish 2006; Wilson and Davies 2009; Koskenniemi et al. 2015). Caregivers gained knowledge about the personalities of the residents by spending time with them, observing their reactions during care, and talking with them. By *showing empathy and respect* they encouraged their feeling of being respected, promoted their self-acceptance, and promoted their willingness to engage in communication (Jordan 2010; Figueredo-Borda and Zabalegui-Yárnoz 2015; Koskenniemi et al. 2015). *Active listening* encouraged residents to disclose themselves—as one nurse recalled her experience:

> I feel … I've done something good one day when I get to talk to the residents about various things, learn about them … things that might be a big deal to them but not to us … So, there are so many things that are intertwined here that it's difficult to explain. I feel like I've done the best I can if I've brought out a smile in the residents … to bring them back. If you manage to say the right things, you can create little moments, and it's amazing what we have managed to get the residents to think about for one, two, five minutes. (Naess et al. 2016)

Stimulating memories was enjoyed by residents as it reminded them of their achievements in life and of the things they cherished (Harmer and Orrell 2008). Some facilities also made attempts to stimulate story-telling for therapeutic purpose. Goddard et al. (2013) investigated the effects of such a project where residents received *dignity therapy*. This approach comprised an interview by a nurse or other trained healthcare professionals, which was recorded and transcribed. The interview was subsequently edited and transformed into a coherent narrative, which was returned to the residents, who could pass the resulting document on to people of their choice—provided they were satisfied. One health care professional told how she perceived the effect of dignity therapy on the social well-being of a nursing home resident:

> She loved the attention, you know, sort of, mum was a great chatter and she likes to talk about the old times. (Goddard et al. 2013)

There were also other methods to promote the self-acceptance of the residents and to give them a feeling of being respected. Minney and Ranzijn (2016) reported about a residential care facility where staff taught residents *strength spotting* which is a technique for maintaining a positive attitude that allows to overcome health setbacks and to remain resilient. Heliker (2009) reported on a project in long-term care facilities where caregivers were encouraged to share stories with residents. Such *story sharing* did not only provide an insight into the personality of the residents, it was also a reciprocal give and take process of respectful telling and listening that focused on what matters to the individual.

Assistance in self-presentation promoted the satisfaction of the need for a self-presentation that was at the same time in line with social standards (Murphy 2007; Naess et al. 2016). For this purpose, the caregivers paid attention to the hygiene and appearance of the residents. They took care that residents groomed their hair, shaved their beard, got on the make-up they wanted, were dressed appropriately and in a way that matched their personality, and they checked their clothes to make sure there were no stains on them. A *tactful dealing with mishaps* served the same purpose (Oosterveld-Vlug et al. 2013a; Koskenniemi et al. 2015). If caregivers behaved naturally and politely when residents accidentally lost urine and were discreet when they needed help in using the toilet, they diminished the feelings of shame of those concerned. Seating arrangements at mealtimes were intended to produce a similar effect for those in need of feeding assistance as they *created a protective environment* (Naess et al. 2016). At the same time, however, this exclusion of residents with disabilities could entail discrimination (Sidenvall 1999).

If residents were still self-reliant, an *allocation of tasks* could meet their desire for work and concern for others, which also fostered their self-acceptance (Ball et al. 2004b; Cooney et al. 2009; Koskenniemi 2015). *Encouraging residents to continue preferred activities* had the same effect (Oosterveld-Vlug et al. 2013b). The above-mentioned *simulation of real life situations* did not only promote social contacts, it was also a source of entertainment (Naess et al. 2016). Even if they had only limited resources, all facilities tried to promote the diversion and entertainment of their residents through *organizing joint activities* which also fostered social contacts as mentioned above (Ball et al. 2000; Koch-Straube 2003; Al-Omari et al. 2005; Kennedy et al. 2005; Murphy 2007; Williams and Warren 2008; Eckert et al. 2009; Svidén et al. 2009; Bradshaw et al. 2012; Kemp et al. 2012; Park et al. 2012; Hwang et al. 2013; Sandhu et al. 2013; Teka and Adamek 2014; Gustavsson et al. 2015; Naess et al. 2016). Some facilities had special staff members called "live enrichment coordinators" who were in charge of organizing such events (Al-Omari et al. 2005), others employed occupational therapists for this purpose (Naess et al. 2016).

There was a broad range of possible joints activities that provided entertainment. First of all, mealtimes had this effect. Delicious food was furthermore a kind of self-reward and a sign of self-acceptance as the residents of a Taiwanese nursing home said with reference to a Chinese saying: "While you are eating, you are the same as an emperor" (Chuang and Abbey 2009). In addition to the meals, there were a number of common activities that provided entertainment. These included parlour games, musical events, performances, excursions, pet therapy, visits from and activities with children, exercises, festivities, and celebrations (Iwasiw et al. 1996; Fiveash 1998; Hweidi 1999; Bergland and Kirkevold 2006; Coughlan and Ward 2007; Tsai and Tsai 2008; Wu and Barker 2008; Cooney 2011; Fraher and Coffey 2011; Philpin et al. 2011; Andrews 2012; Falk et al. 2013; Nakrem et al. 2013; Thomas et al. 2013; Teka and Adamek 2014; Adra et al. 2015; Gustavsson et al. 2015; Naess et al. 2016; Rekawati et al. 2018). In some institutions there were also group discussions to meet the need for reflection (Teka and Adamek 2014), while other facilities tried to satisfy the need for work and productivity through opportunities such as cooking, gardening, crafts, and creative design (Iwasiw et al. 1996; Fiveash 1998; Cooney 2011; Fraher and Coffey 2011; Philpin et al. 2011; Thomas et al. 2013; Chuang et al. 2015). Mainly, however, these activities were tailored to meet the needs of the average resident. As a consequence, residents with a higher level of capabilities felt insufficiently challenged and those with an individual interest felt homogenized (Tucket 2007; Chang 2013; Stevens et al. 2015). In order to meet the different needs of male and female residents, some facilities tried at least to offer *gender specific activities* like men-only luncheons with speakers and topics on men's issues or bingo which attracted mainly women (Al-Omari et al. 2005; Kemp et al. 2012).

There were, however, not always efforts to meet identity-related needs. A closer investigation of staff's knowledge about the personalities of residents revealed that despite good intentions to provide person-centred care staff members had *no concrete idea about their likes and dislikes* and how to respond to them. As one participant replied:

> Specifically, just for him? Well, I think it's always a question of giving somebody attention and taking somebody seriously. Behave nicely to someone, respond to what someone says… Really, I think it's mainly the kind of things that apply to anyone. (Oosterveld-Vlug et al. 2013b)

In some cases, organizing joint activities was not meant to create a meaningful event for residents but to produce an outcome that was believed to have therapeutic value. Koch-Straube (2003), for example, describes music therapy sessions aimed at improving the mood of the participating residents, but since these sessions were not related to their individual needs, they had a rather manipulative character. In his meanwhile classical study about an American nursing home, Gubrium (1997) provides an example of a reality orientation therapy session which was similarly outcome-oriented and manipulative. In such sessions participating residents were asked to read items on a chart and then they were quizzed on the content. Correct answers were those that corresponded to the chart and they indicated that the resident was oriented. An excerpt from one such session illustrates this approach.

> Aide: [pointing to the weather on the RO board that reads 'raining'] What's the weather like today, Emma?
> *Emma turns her head slightly and quickly looks out the window*
> Emma: Well, it looks like the sun is shining kinda bright.
> *The sun happens to be shining at the moment*

> Aide: Are you sure? It says, it's raining. Doesn't it? [Finger still pointing to the board]
> Emma: Well, it doesn't look like it from here.
> Aide: What does it say here, Emma? [Directing Emma's attention to the board]
> Emma: It says it's raining.
> Aide: [Warmly] That's correct. Very good. (Gubrium 1997)

With their exclusive focus on the improvement of cognitive function, such *sessions were detached from the lifeworld* of the residents and their concerns (in this particular case reality orientation was even detached from reality). Not surprisingly, residents felt reminded of school and disliked to participate. While in this case the residents were kept busy with activities that were meaningless to them, in other cases they were denied activities they wanted to do. Some residents complained that staff *prevented them from helping* in the facility (Koskenniemi et al. 2015; Palacios-Ceña et al. 2016a; Zimmerman et al. 2016)

> I asked once or twice let me help to clean the table, but they (nurses) said that they don't need help. (Koskenniemi et al. 2015)

> They said that they couldn't because I was a resident and not a worker. (Palacios-Ceña et al. 2016a)

Worse than the disregard of such needs was the *lack of respectful treatment* that was experienced by many residents (Grant et al. 1996; Hellström and Sarvimäki 2007a, b; Dobbs et al. 2008; Tsai and Tsai 2008; Williams and Warren 2008; Timonen and O'Dwyer 2009; Falk et al. 2013; Teka and Adamek 2014; Chuang et al. 2015; Stevens et al. 2015; Donnelly and MacEntee 2016; Lung and Liu; Zimmerman et al. 2016). Letting them wait, showing no interest in their concerns and opinions, and talking to them in a derogatory way did not only create feelings of powerlessness, it also had a negative impact on their self-esteem and prevented the satisfaction of their desire for self-presentation in order to gain the respect of others. Underlying such a lack of respect was an ageism that perceived older people as senile and incapable of making their own decisions, and often manifested itself in an infantilizing treatment.

> I find it insulting; they talk above you like you are a mute, deaf and dumb … They think we're all retarded and about to wet our pants at any moment and not having a brain in our heads … It is true that there is such a stereotype about old age … They talk to you like you are a child: 'oh that was so clever of you to tie your shoe like that, good boy'. (Donnelly and MacEntee 2016)

Some residents also reported about *discrimination* due to their race or their social status (Shin 2008; Hutchinson et al. 2011). Ethnic minorities like African Americans had experienced racism throughout their life and were also exposed to it in long-term care by the behaviour of caregivers and roommates. This behaviour was stood in marked contrast with the *privileged treatment of higher status residents* that made the others aware of their lower status (Dobbs et al. 2008; Zimmerman et al. 2016).

> They treat me pretty well because of my husband; he was a judge. Doctors and judges and their wives are treated differently. (Dobbs et al. 2008)

5.4.7 Behavioural and Attitudinal Reactions

Despite their restricted opportunities residents tried to satisfy their identity-related needs. A good deal of their time was spent on *individual activities* (Fiveash 1998; Hweidi 1999; Ball et al. 2000; Bergland and Kirkevold 2006; Andersson et al. 2007; Coughlan and Ward 2007; Svidén et al. 2009; Tsai and Tsai 2008; Hauge and Heggen 2008; Williams and Warren 2009; Andrews 2012; Park et al. 2012; Falk et al. 2013; Martinsson et al. 2013; Nakrem et al. 2013; Thomas et al. 2013; James et al. 2014; Teka and Adamek 2014; Gustavsson et al. 2015; Minney and Ranzijn 2016; Slettebo et al. 2016; Rekawati et al. 2018). Self-care, household tasks (if they had a single room equipped with own furniture), needlework, or crosswords gave them the feeling of having something to do and to be productive. Reading and in some cases the use of a computer kept their mind busy or provided some entertainment. Diversion was also found by listening to the radio, watching television, observing other residents, receiving visits from volunteers, or participating in excursions with the family. Relaxation was found when residents withdrew to have a rest or spent time with contemplation or watching the nature. Beside this, residents *participated in* the above-mentioned *joint activities* that were organized by the staff.

To some extent residents also showed *social engagement*. If they were able and allowed to do so, they helped in the facility, for example, by contributing to the preparation of meals or festivities, caring for facility pets, or working in the garden provided these options were available (Ball et al. 2004b; Williams and Warren 2008; Herrmann and Flick 2011; Perkins et al. 2012; Teka and Adamek 2014; Figueredo-Borda and Zabalegui-Yárnoz 2015). Others helped care dependent residents by providing practical support like pushing their wheelchair or bringing them something to drink, or by cheering them up and giving emotional encouragement (Hweidi 1999; Kennedy et al. 2005; Dobbs et al. 2008; Kemp et al. 2012; Park et al. 2012, 2013; Perkins et al. 2012; Sandhu et al. 2013; Minney and Ranzijn 2016). If it was a part of the organizational structure, some residents could act as representatives of the interests of their roommates (Svidén et al. 2009). Some facilities also edited an internal newspaper that allowed residents to submit contributions, and in a Chinese facility residents were also engaged in the education of young people of the surrounding communities by organizing symposia for them (Cheng et al. 2011). Beside these activities, older persons *cultivated their memories* in order to maintain or regain their self-esteem (Harmer and Orrell 2008; Goddard et al. 2013). This was particularly suitable for those who were less able to be active and was supported by dignity therapy in some facilities.

5.5 Long-Term Care Facilities and Development-Related Orientations of Action

Moving into a nursing home creates a new framework for the satisfaction of identity-related needs. It is a change that threatens the established balance between maintaining old habits and searching for new perspectives. In contrast to younger persons who tend to search for new perspectives and suffer from feelings of stagnation that may result in a midlife crisis if they fail to do so, older persons are naturally more inclined to the preservation of their past. Losing their past poses a serious threat to their identity, which is further aggravated by the fact that their future perspective consists of their approaching death. Moving into a long-term care facility is thus an end life crisis, and older persons may respond to this situation by attempts of denying the closeness of their death or by facing it. At the same time they have to find a balance between scepticism and hope that allows them to deal with their situation without succumbing to despair or deceptive expectations. Table 5.6 provides an overview over these development-related orientations of action and their satisfaction, their influencing factors, and the behavioural and attitudinal responses of the older persons.

Table 5.6 Development-related orientations of action, influencing factors, behavioural and attitudinal reactions

Orientations of action and their satisfaction	
Attachment to the past	Attachment to the old home
	Maintaining old lifestyle
	Cultivation of memories
	Desire for cultural continuity
	Insisting on routines of care
	Abandoning old habits
	Efforts to forget the old home
Satisfaction of attachment to the past	Initial fear and uncertainty
	Shock at admission
	Sadness about loss of home
	Sadness about loss of previous identity and life
	Not at home in the new home
	Feeling betwixt and between
	Finding some continuity
	Homelike atmosphere
Searching new perspectives	Inclined to learn something new
	Desire to re-establish a feeling of being at home
	Developing new routines
	Resistance to adapt
Satisfaction of searching new perspectives	Discovering a new life
	Getting a new sense of belonging
	Stagnation
Denial of adversities	Avoidance of confrontation with mortality and death
Satisfaction of denial of adversities	Life without undue worries and fears
	Sudden fear of death
Facing adversities	Preparing themselves and others for own death
Satisfaction of facing adversities	Enabled to deal with the approaching end
Scepticism	Downsizing expectations
	Restricted expectations for an improvement

Table 5.6 (continued)

Satisfaction of scepticism	Gradual adaptation
Hope	Making the best out of it
	Religious expectations
Satisfaction of hope	Satisfied despite limitations
	Enjoying the moment
	Well-being in spite of illness
	Religious comfort
	Peace and solace in the face of death and dying
	Being hopeless and resigned
Influencing factors	
Environmental factors	Homelike environment
	Impersonal and institutional atmosphere
	No match with cultural background
Development-related care	*Same as in Tables 5.4 and 5.5*
	Religious ceremonies
	Allowing to grieve
Behavioural and attitudinal reactions	Cultivating memories
	Religious practices

5.5.1 Attachment to the Past Versus Searching New Perspectives

5.5.1.1 Attachment to the Past

A motive of central importance for residents in long-term care facilities was their *attachment to their old home* (Hutchinson et al. 2011; Chin and Quine 2012).

> I like to have my own spot where I can be still, where I can enjoy my home, where I can be on my own. (Chin and Quine 2012)

Their old home was the place they had shaped all their lives. It was a material expression of their personality and enclosed their identity like a protective shell. It secured their privacy and provided a connection to a familiar environment. At the same time, residents sought to *maintain their old lifestyle* (Harmer and Orrell 2008; Cooney 2011; Philpin et al. 2011; Palacios-Ceña et al. 2013; James et al. 2014; Roberts and Bowers 2015). They wanted to continue their usual routines, pursue their old hobbies, and keep up their old contacts with families and friends. If this was not possible, they resorted to the *cultivation of their memories* which also served to promote their self-acceptance (Koch-Straube 2003; Hjaltadóttir and Gustafsdóttir 2007; Harmer and Orrell 2008; Melin-Johansson et al. 2014; James et al. 2014; Oosterveld-Vlug et al. 2014). Members of ethnic minorities had an explicit *desire for cultural continuity* since living away from their homeland made them feel that the culture of their host country stood in contrast to their familiar way of life (Shin 2008; Hutchinson et al. 2011; Andrews 2012; Martinsson et al. 2013; Park et al. 2013). They longed for the kind of food they had been used to since childhood, preferred to watch television from their home country, wanted to talk to residents of the same cultural background, and favoured to have caregivers who spoke their own language. Some residents were explicitly concerned about *staying in connection to their cultural roots* (Hutchinson et al. 2011; Martinsson et al. 2013). They were eager to celebrate the festivities of their homeland or wanted to learn more about its history and traditions.

> I have always been interested in history …but my eyes get so tired … I wish they could find something they could read to me about my native country. (Martinsson et al. 2013)

Residents who had become used to life in the facility tended to maintain their habits by *insisting on routines of care* (Koch-Straube 2003). They wanted to keep their seat at mealtimes, which had once been allocated to them, and insisted on the timing and procedure of their personal care. However, not everybody was concerned to the same extent about preserving the past. Some residents told that they had *abandoned old habits*. Everyday routines, such as caring for hygiene, had become less important to them, which increased their readiness to accept care as it was (Heid et al. 2016), and there were also those who felt no sadness about leaving their old homes since they were no longer attached to their habits and belongings (Iwasiw et al. 1996). Some residents even made *efforts to forget their old home* and forced themselves not to look back (Cooney 2011; Chang 2013).

> I said to my daughter, 'Don't leave my stuff, even my spoon. Throw all of my stuff away. I will wait for my passing here from now on. I am going to think of this place as my home. Throw it all away.' I have forgotten everything, since I didn't go home. (Chang 2013)

5.5.1.2 Satisfaction of Attachment to the Past

Some older persons reacted to the loss of their familiar environment with an *initial fear and uncertainty* when they entered the facility that had to become their new home (Iwasiw et al. 1996; Cooney et al. 2009). They felt overwhelmed by the newness of everything, and were shy to establish contacts to other residents.

> There's a lot of fearfulness because you leave a world that you've known all your life. (Iwasiw et al. 1996)

> You've got to learn the ropes. Nobody tells you anything. (Heliker and Scholler-Jaquish 2006)

For many residents, however, losing their old home resulted in a *shock at admission*—especially when they had been forced to move in against their will since this was a blow against their self-determination (Iwasiw et al. 1996; Hweidi 1999; Falk et al. 2013; Teka and Adamek 2014).

> A very big shock. A younger person wouldn't understand it. I can't say that I ever felt worse in my whole life time. (Iwasiw et al. 1996)

> I can't remember my own feelings the day I moved in. It's just a blank. Whether I just wanted it wiped out, maybe that's what happened. (ibid.)

Out of this shock evolved a permanent *sadness about the loss of their home* (Iwasiw et al. 2003; Dobbs 2004; Bergland and Kirkevold 2006; Heliker and Scholler-Jaquish 2006; Bland 2007; Hjaltadóttir and Gustafsdóttir 2007; Walker and Curry 2007; Cooney et al. 2009; Cooney 2011; Fraher and Coffey 2011; Martinsson et al. 2013; Nakrem et al. 2013; Teka and Adamek 2014; Stevens et al. 2015; Canham et al. 2016; Shaw et al. 2016; Koppitz et al. 2017).

These residents felt uprooted and homeless and their sorrow could be exacerbated by the knowledge of what happened to their previous home.

> I want to go back to my apartment; it's a whole house full of memories. The only thing I've regretted is falling and being where I am now [nursing home]. (Heliker and Scholler-Jaquish 2006)

> We left it immaculate […] They've ripped everything up, the garden, everything. Edgar said to me 'leave it, gone, it's gone, leave it.' But I can't. […] And he said 'done, it's finished.' That's our life gone, that's part of our life gone. But that was my life. I mean, I've been there fifty four years, my husband was there since he was about eight. (Shaw et al. 2016)

These feelings were associated with *sadness about the loss of their previous identity and life* since they lost contacts to their old friends and were unable to continue their habits and routines (Iwasiw et al. 1996; Koch-Straube 2003; Dobbs 2004; Bergland and Kirkevold 2006; Heliker and Scholler-Jaquish 2006; Svidén et al. 2009; Andrews 2012; Chang 2013; Nakrem et al. 2013; Palacios-Ceña et al. 2013; Oosterveld-Vlug et al. 2014; Cho et al. 2017; Koppitz et al. 2017).

> You don't know what it's like…you lose your identity for being able to do what you want to do when you want to do it. (Heliker and Scholler-Jaquish 2006)

> So at the end of my life you had to settle for this – not that I lay awake about this, but I do think it gets you very much down. (Iwasiw et al. 1996)

Residents from ethnic minorities experienced at times some *cultural alienation* since their roommates did not speak their own language and caregivers did not understand the cultural background of their habits and routines (Martinsson et al. 2013). In sum, many residents did *not feel at home in their new home* and wanted to return. Some of them believed that their stay was only temporary and their hope to return was nourished by the fact that their old home was still existent:

> I just brought the essentials… my furniture is still at home and I've been here for 6 months now. My daughter is taking care of my apartment while I'm here. (Falk et al. 2013)

Others were aware of the advantages they had from staying in the facility but they could not get accustomed to institutional life. Hence, they *felt betwixt and between* the old and the new way of life and remained ambivalent in their feelings for the long-term care facility (Iwasiw et al. 1996; Bergland and Kirkevold 2006; Heliker and Scholler-Jaquish 2006; Bland 2007; Bollig et al. 2016). In the interviews, these residents expressed their views on the facility in statements such as: "I wouldn't say anything against it…." (Iwasiw et al. 1996), but what remained unsaid was an objection like: "It is possible to stay here, but I would rather have lived at home" (Bergland and Kirkevold 2006).

There were also residents who could satisfy to some extent their desire to maintain old habits since they *found some continuity*. Some of them were able to maintain old contacts since the facility was located in their familiar environment (Iwasiw et al. 1996; Falk et al. 2013; Schenk et al. 2013; Minney and Ranzijn 2016).

> Mhm. Well. As I said, the whole environment to start with, yes, the, the feeling of being at home yes [clears throat] then, as I said, a mate here, a mate there, just off- off the cuff I could name you three… three… um um… three men who um live on the premises here yeah, or um acquaintances, and women too, it's not like that, no - but the feeling of being at home is definitely worth a lot. (Schenk et al. 2013)

Another resident told how she found comfort in being still able to visit her old home.

> I can go out to my home from here; it was very strange when I went out first but I feel more relaxed now. I am glad to come back to the company. (Fraher and Coffey 2011)

Residents from ethnic minorities sometimes found a caregiver from their own cultural background and his or her presence increased their sense of familiarity (Martinsson et al. 2013). The most important thing for gaining some sense of continuity was the possibility of personalizing one's own space by bringing own furniture and other belongings to the facility (Iwasiw et al. 2003; Bergland and Kirkevold 2006; Hjaltadóttir and Gustafsdóttir 2007; Murphy et al. 2007; Cooney et al. 2009; Cooney 2011; Falk et al. 2013; Nord 2013; Hillcoat-Nalletamby 2014; Shin 2015)

> I am very grateful that my room is big enough, so that I have space for some private furniture. It is important to have my own furniture. In a way I feel more at home when I can sit among this furniture (Bergland and Kirkevold 2006)

Several residents were also *able to continue old habits*—even if this was only possible to a lesser extent (Ball et al. 2004b; Bland 2007; Harmer and Orrell 2008; Philpin et al. 2011; Chin and Quine 2012; Andrew and Wilson 2014; Hillcoat-Nalletamby 2014; Minney and Ranzijn 2016). This was the case when they had the opportunity to work or to pursue a valued hobby. The desire for continuity was also satisfied when the facility had a *homelike atmosphere* that brought back old memories. Such feelings could be evoked by a café inside the facility or a garden that reminded residents to pleasures they had experienced in their previous life.

> It is nice and cozy in front of the fireplace 'cause in the winter time that fire's going and it's beautiful sitting around on the comfy suite there and having a cup of coffee. (Andrew and Wilson 2014)

> I love the feeling when I'm out in the garden. It takes me back to my childhood. (Raske 2010)

First and foremost, however, the feeling of being at home depended on the social atmosphere, i.e. residents' familiarity with roommates and staff (Ball et al. 2004a; Cooney 2011):

> It's real homely … it feels just right … there's an atmosphere of home about it that you don't feel you're in a strange place at all… There's no feeling of loneliness about it, you know it's a companionable place. (Cooney 2011)

5.5.1.3 Searching New Perspectives

Despite their old age and the losses they had experienced some residents were still *inclined to learn something new*. For them, life was a continuous process of learning.

> If you learn to accept things as they are, use time that otherwise would be empty and listen to tapes, then you can go on learning until you die. (Hjaltadóttir and Gustafsdóttir 2007)

> I just love to learn. Ever since I left school I wanted to learn things. I just love it and now, heaven forbid, I'm trying to teach myself to play the mouth organ! I've bought lessons from the Internet. I'm doing a two year Diploma course. I've got time to focus on that now. (Minney and Ranzijn 2016)

However, the search for new perspectives was more often concerned with a *desire to re-establish a feeling of being at home* and to make the unfamiliar familiar. In this sense residents searched for new contacts and tried to discover pleasant aspects in their new home. For the same reason, several residents tried to learn the rules of their new environment and to *develop new routines* (Iwasiw et al. 1996; Hutchinson et al. 2011). Residents, however, who were strongly attached to the past and could not overcome the loss of their home were reluctant to discover something positive in their new environment and showed a *resistance to adapt* (Dobbs 2004).

5.5.1.4 Satisfaction of Searching New Perspectives

A minority of residents were able to *discover a new life* in their long-term care facility (Iwasiw et al. 1996; Boggatz et al. 2009; Bradshaw et al. 2012; Shaw et al. 2016). These were those who were inclined to life-long learning and those who had voluntarily moved in to free themselves from social constraints and attain an individual way of life. More commonly, however, the residents found something familiar in the unfamiliar and *developed a new sense of belonging* to the new place (Iwasiw et al. 1996; Bergland and Kirkevold 2006; Heliker and Scholler-Jaquish 2006; Bowers et al. 2009; Jordan 2010; Cooney 2011; Chin and Quine 2012; Oosterveld-Vlug et al. 2013a; Bollig et al. 2016; Canham et al. 2016).

> I think differently [about being in the nursing home] than I did in the beginning when I came here … because I now feel more connected [to the nursing home] than I did when I came here. I do feel more at home. (Bollig et al. 2016)

> I consider this my home now, but not a home the way I am used to. I have a totally different attitude towards my surroundings now. (Bergland and Kirkevold 2006)

Residents, however, who were unable to adapt had a feeling of *stagnation* despite their efforts to find some entertainment and diversion (Fiveash 1998; Coughlan and Ward 2007; Tucket 2007; Oosterveld-Vlug et al. 2014).

> I feel that my life has no future at the moment …. I watch the tennis and I watch the football and that — on TV, and that just fills in time. (Tucket 2007)

5.5.2 Denial of Adversities Versus Facing Adversities

That staying in a long-term care facility would mean a loss of the old home was apparent to many older people even before they moved in. As we saw in Chap. 2, many of them avoided to think about this possibility and denied care needs that might force them to move in. Those who already lived in a long-term care facility could not ignore this situation, but they had to respond to the fact that this was most probably the last stop in their lives. They had to find a balance between a denial of their approaching death which to some extent was necessary to maintain a future perspective and the tendency to face their unavoidable end in order to be prepared for it.

5.5.2.1 Denial of Adversities

Staying in a long-term care facility implied a threat to be confronted with death. Witnessing other residents' physical decline and their process of dying reminded the older persons to their own, final destiny. To maintain a positive attitude required the *avoidance of a direct confrontation with mortality and death* (Tsai and Tsai 2008; Walker and Paliadelis 2016). This denial was necessary to protect a vulnerable state of mind. As one resident put it:

> It is upsetting to see people decline. I don't allow myself to get close. (Walker and Paliadelis 2016)

As we will see in the following chapter, this denial was rooted in a culture where confrontation with death was avoided and where families and caregivers sought to reinforce this attitude in the older persons.

5.5.2.2 Satisfaction of Denial of Adversities

As long as residents could avoid the unwanted confrontation with death, they could continue their *life without undue worries and fears*. However, there were always situations where a confrontation with death was unavoidable and such encounters triggered a *sudden fear of death*. A resident in a Taiwanese nursing home, for example, described his anxiety when he had to share his room with a dying person:

> I was scared when I had to live with an unconscious person. It [seeing that person] made me feel that I could be in his situation in the future. I was also afraid that he would pass away in this room. You know it is not good for Chinese people to see someone die in the same room. This would make me feel the soul or ghost is surrounding the room, which is a symbol of misfortune. And maybe I would be the one following him soon. (Tsai and Tsai 2008)

5.5.2.3 Facing Adversities

Not everybody, however, was scared of the approaching end of life. Instead, these residents tried to *prepare themselves and others for their own death* (Hjaltadóttir and Gustafsdóttir 2007; Shrestha and Zarit 2012; Falk et al. 2013; Chuang et al. 2015). They had a desire to say goodbye to family and friends and took precautions about their funeral.

> I have told my daughter (about my death) and wanted to say a nice goodbye. She doesn't want to listen to me. She becomes angry when I mention it. I want to talk, but she doesn't want to listen. (Chuang et al. 2015)

> I have told my son that I want to be buried beside my wife. I don't want to be cremated. (ibid.)

5.5.2.4 Satisfaction of Facing Adversities

Residents who faced their approaching death were devoid of self-delusion. This saved them from undue fears that were experienced by those who were inclined to a denial of death and *enabled them to deal with their approaching end*. If there was something they desired in the face of the unavoidable end of life, it was not an extension of life or an improvement of health but a fast and painless process of dying:

> It's just a part of life, I guess. We'll all end up like this if you live long enough graced with a long life. Having that said… for my own part I really hope that when it starts going downhill it will be fast. The worst thing that could happen is if I end up like one of those in need of incontinence pads and feeding tubes. I hope that I'll manage independently all the way to the end. That's really my only wish for the future. (Falk et al. 2013)

5.5.3 Scepticism Versus Hope

Staying in a long-term care facility and dealing with the loss of the old home required also a balance between scepticism and hope. On the one hand, residents had to come to terms with things as they were and not to indulge in deceptive hope. However, a one-sided scepticism could result in hopelessness and despair. Therefore, it had to be balanced by a tendency towards hope which enabled older persons to discover something positive even in negative circumstances.

5.5.3.1 Scepticism

In view of their frailty, which had resulted in the loss of their old homes, many older persons tended to accept the situation as it was. They made the decision to be satisfied with less and this *downsizing of expectations* was an attempt to adapt to the loss of a positive future perspective (Grau et al. 1995; Ball et al. 2004a; Bergland and Kirkevold 2006; Walker and Curry 2007; Timonen and O'Dwyer 2009; Fraher and Coffey 2011; Bradshaw et al. 2012; Chin and Quine 2012; Nakrem et al. 2011; Nakrem et al. 2013; Falk et al. 2013; Oosterveld-Vlug et al. 2013a; Oosterveld-Vlug et al. 2014; Taylor et al. 2014; Iden et al. 2015; Donnelly and MacEntee 2016; Walker and Paliadelis 2016).

> You don't need more when you are so old (Nakrem et al. 2013)

Although they were not pleased about their situation, they tried to convince themselves that staying in a long-term care facility was still the best that could have happened to them:

> You are more likely to resign yourself to those things, because there's no alternative. I should be pleased I'm here at all. (Oosterveld-Vlug et al. 2013a)

Downsizing expectations implied that residents accepted a loss of control, adapted to routines of care, got satisfied with limited opportunities for work or entertainment, and remained aware of their own mortality.

> You can't do anything. You sit in your room on your own… I knew I had to get used to it because I knew I'd be here till they cart me out. Likewise Leo said: It's a part of it now… But, no, you know beforehand when you get here, that it's the last stop. (Walker and Paliadelis 2016)

Not surprisingly, these residents had only *restricted expectations for an improvement* in their own condition when facilities made attempts to promote their health. One resident, for example, who participated in an exercise program said:

> I'm very old. You can't expect to be made new when you're old. I mean, everything else is wearing out on us, they can't give you new things, so that's the way to look at it, isn't it? (Stathi and Simey 2007)

> At my age, I just have to accept the health decline. So I don't spend much time reflecting on this. (Iden et al. 2015)

5.5.3.2 Satisfaction of Scepticism

Residents who tended to be sceptical and downsized their expectations experienced a *gradual adaptation* to life in the long-term care facility (Andersson et al. 2007; Andrews 2012; Cooney 2011; Kemp et al. 2012). They had no hopes that could be disappointed and simply got used to stay there. In the course of time they became familiar with their new environment, established some social contacts and found some opportunities for shaping their life. One resident described his adaptation after some period of time:

> I feel closer to those people that I see, those people who are closer to me in the dining area, those people that are closer to me in the hallway, that I pass more often going to and fro. (Kemp et al. 2012)

Although this statement does not suggest any real closeness to the roommates, it shows a certain degree of habituation which rendered the stay in the facility at least bearable.

5.5.3.3 Hope

A one-sided downsizing of expectations, however, did not necessarily produce a degree of satisfaction. It also required a tendency to hope that implied the ability to discover something positive even in negative situations. A common way to find something positive while staying in a long-term care facility was to think in a positive way and the attempt to *make the best out of it* (Iwasiw et al. 1996; Ball et al. 2000; Bourrett et al. 2002; Dobbs 2004; Bergland and Kirkevold 2006; Heliker and Scholler-Jaquish 2006; Bland 2007; Stathi and Simey 2007; Cooney et al. 2009; Cooney 2011; Bradshaw et al. 2012; Chin and Quine 2012; Falk et al. 2013; Oosterveld-Vlug et al. 2013b, 2014; Stevens et al. 2015; Bollig et al. 2016; Shaw et al. 2016; Slettebo et al. 2016; Koppitz et al. 2017):

> That should be one's aim: to lead a reasonably happy existence. It is no great fun in being unhappy all the time and revelling in your unhappiness saying, 'Oh goodness me, life is a bore', one can say that, I say that getting old is a bloody awful thing, but, ah! There you are! You've got to make the most of it. (Stathi and Simey 2007)

According to these residents adaptation to losses and finding a new perspective was a matter of mind:

> I made up my mind to go ahead with what I can do. We have to play the cards we are dealt (Heliker and Scholler-Jaquish 2006)

> I sat down and reasoned with myself and decided that I wanted to move here and that would feel at home, that the food would taste great and that all the people here were kind-hearted. If I didn't set my mind to it, it would be impossible for me to live like this… so that is what I did and that have worked out just fine. Does that sound crazy to you? (Falk et al. 2013)

This attitude allowed them to overcome their initial rejection of staying in a long-term care facility. A strategy that facilitated these attempts to think positive was the above-mentioned comparison of one's own situation with the situation of others who were worse of—a strategy which also helped to promote a positive self-perception.

A way to find something positive even in the face of mortality and death was to have *religious expectations* (Hweidi 1999; Bland 2007; Hutchinson et al. 2011; Shrestha and Zarit 2012; Chang 2013; Oosterveld-Vlug et al. 2014; Adra et al. 2015; Chuang et al. 2015; Iden et al. 2015; Heid et al. 2016). Residents, who had such expectations, read the scriptures of their religion and spent their time in prayer hoping to soothe and overcome their sorrow.

> When you truly put your faith in God and let him direct you in your life you will be able to face any difficulties you find yourself going through. I have confidence that his almighty can guide me. Thank God, I am a strong believer and I love praying. I love to be honest and tell the truth all the time and this is very important for my quality of life. (Adra et al. 2015)

> What is required for happiness? I just sing and recite the hymn of God. That is main thing… Singing hymn of the God is required to experience and enjoy happiness permanently […] we must console our mind by remembering the Almighty. (Shrestha and Zarit 2012)

5.5.3.4 Satisfaction of Hope

When older persons were inclined to make the best out of their situation, they became *satisfied despite limitations* (Bland 2007; Walker and Curry 2007; Hutchinson et al. 2011; Iden et al. 2015; Walker and Paliadelis 2016)

> So I haven't got that much longer to live so… so I'll be alright. Yes, that's what I mean, so I don't worry about that. It's as good as I'll get. (Walker and Paliadelis 2016)

Since they had no far-reaching goals for the future, wishes and hopes were temporarily satisfied when residents found pleasure in small things and *enjoyed the moment* (Walker and Curry 2007; Tsai and Tsai 2008; Nakrem et al. 2011; Melin-Johansson 2014; Oosterveld-Vlug et al. 2014; Minney and Ranzijn 2016; Shaw et al. 2016). Sitting in the sun and doing nothing or playing with a pet could be a source of joy. One resident described how he enjoyed a trip on houseboat:

> Oh that's great fun! It's most relaxing and the staff look after us really well. The food's lovely and it's just relaxing just to sit there. I wander around the deck looking at everything I can see (which is not that much), but what I can see, I enjoy. (Minney and Ranzijn 2016)

Such positive experiences could produce a *well-being despite illness* (Bergland and Kirkevold 2006; Nakrem et al. 2011; Behr et al. 2014; Minney and Ranzijn 2016). This was more than the above-mentioned satisfaction despite limitations, since it involved an inner thriving that outweighed these limitations. A male resident with paraplegia, for example, claimed that his health was "darn good" (Nakrem et al. 2011) and a female resident explained how she achieved well-being despite her arthritis by engaging in joyful activities:

> One thing that stops me from doing a lot of things is my arthritis, yeah that can hold you back a bit. But luckily I've got my daughter here and she comes and picks me up and we go out for coffee and we have lunch out sometimes and I'm quite happy with that. And I like to read, you know, books. I'm really quite content living (Minney and Ranzijn 2016).

Beside this temporary joy and pleasure many residents found hope in *religious comfort*. Religious rituals and practices provided spiritual well-being that helped overcome mental and even physical suffering. A resident in a Jordanian nursing home, for example, told how he got rid of his nightmares since he put the Koran under his pillow:

> I'm an illiterate man who can't read or write. I see frightful nightmares while sleeping every night. The presence of a text of the Holy Koran ensures that I'm not going to see nightmares again. (Hweidi 1999)

Christian residents in an Ethiopian care facility for the poor described how they compensated the lack of medication:

> Why should we seek medical service rather than God's support? Holy water is our medicine. (Teka and Adamek 2014)

In the same way, the Hindus found comfort in their own religion:

> When one hears Lord Krishna's flute music, one does not recall sufferings and troubles. (Shrestha and Zarit 2012)

> Where is peace? To mutter the name of God repeatedly gives much more peace and happiness. He has created the world. If one is naked and hungry, he is kind to him. He resides in the heart of everyone. (ibid.)

A satisfaction of hope could also help to find *peace of mind in the face of death and dying* (Hjaltadóttir and Gustafsdóttir 2007; Melin-Johansson et al. 2014; Shin 2015; Shaw et al. 2016). These residents appreciated life and enjoyed its moments, but were not worried about prolonging it since they felt no fear of death.

> I'm not keen on this long life that everyone is striving for, on the other hand I admire life, it has given me many things, both hard work and also happiness. (Hjaltadóttir and Gustafsdóttir 2007)

Residents in facilities run by a religious congregation described how they found hope and solace in ceremonies for the dying that helped them to overcome their own fear of death and to await an afterlife.

> Because… when you die, nuns all gather together around the deathbed. They pray, they sing… beauuuuuuutiful songs… They accompany you to the doorstep of the heaven… (Shin 2015)

Others, however, were unable to overcome their suffering. After being abandoned by their family, they felt that they had lost their purpose in life, and they became *hopeless and resigned* (Ball et al. 2000; Koch-Straube 2003; Andersson et al. 2007; Coughlan and Ward 2007; Tsai and Tsai 2008; Hutchinson et al. 2011; Melin-Johansson et al. 2014; Cho et al. 2017; Mohammadinia et al. 2017). The only wish they had was to die as soon as possible

> My sons don't want to care for me, so they sent me to this place. I can't do anything. All I can do is eat; [I am a] useless person. I hope to pass away as soon as possible. (Tsai and Tsai 2008)

> I don't look forward to anything. I don't think much about the future. I just live day-to-day and expect it to end up very shortly. In fact I hope it does. (Ball et al. 2000)

5.5.4 Influencing Factors

5.5.4.1 Environmental Factors

Since physical decline was the main reason for an admission to a long-term care facility, it disrupted the balance between maintaining old habits and searching for new perspectives and triggered the crisis that had to be resolved by finding a new balance between scepticism and hope. This process could be facilitated or hampered by the environmental factors that also influenced the satisfaction of body-related, social, and identity-related orientations of action. Of particular importance for the balance between maintaining old habits and searching a new perspective was the atmosphere of a facility. A *homelike environment* that reminded residents to places of their previous life enabled them to find something familiar in the unfamiliar and promoted their sense of belonging (Bergland and Kirkevold 2006; Murphy et al. 2007; Hauge and Heggen 2008; Cooney 2011; Bradshaw et al. 2012; Barnes et al. 2013; Andrew and Wilson 2014; Adra et al. 2015; Nakrem 2015). This could be further enhanced if they were allowed to furnish their own space with private belongings that were memories of their past. In contrast, an *impersonal and institutional atmosphere* that imposed schedules and routines on residents and did not provide opportunities for recreation and the establishment of social contacts deprived older persons of their sense of home (Canham et al. 2016). Furthermore, the atmosphere and style of a facility could *not match the cultural background* of immigrants—even if it was homelike for the majority of their roommates (Andrews 2012; Martinsson et al. 2013).

5.5.4.2 Development-Related Care

The treatment of the residents also had an influence on the satisfaction of their development-related needs. Care related to social and identity-related orientations of action played a key role for the failure or success to find a new balance between maintaining old habits and searching for new perspectives. Getting acquainted with a residents' biography, active listening, and supporting reminiscence did not only satisfy older persons' desire for respect and self-esteem, as mentioned above, it also helped them to establish a connection to their past. Allocation of tasks, promotion of social contacts and organisation of common activities, did not only satisfy social and identity related needs, but also offered the possibility to discover new perspectives if they were tailored to the preferences and interests of the older persons. *Religious ceremonies* helped to satisfy their need for hope (Iwasiw et al. 1996; Bergland and Kirkevold 2006; Fraher and Coffey 2011; Andrews 2012; Falk et al. 2013; Nakrem et al. 2013), and *allowing them to grieve* (Heliker and Scholler-Jaquish 2006) could alleviate their sorrow if they became hopeless and resigned.

5.5.5 Behavioural and Attitudinal Reactions

Since an admission to a long-term care facility meant a major change in the life and was often experienced as a crisis, older persons had to react with a readjustment of their development-related orientations of action which was also reflected in their behaviours. Cut-off from their homes and their previous lives they could try to some extent to search for new perspectives. Another way of staying connected to the past was *cultivating memories*, which also helped them to maintain their self-esteem, as mentioned above (Harmer and Orrell 2008; Goddard et al. 2013). If they were confronted with the death of roommates, they could try to face this final adversity. To the awareness of their approaching end, they could react by downsizing their expectations, which also helped them to cope with the loss of physical abilities and self-reliance. As a counterbalance, many tried to strengthen their hope, mainly with the help of *religious practices* (Hweidi

1999; Ball et al. 2000; Al-Omari et al. 2005; Bergland and Kirkevold 2006; Bland 2007; Hutchinson et al. 2011; Park et al. 2012; Shrestha and Zarit 2012; Chang 2013; Adra et al. 2015; Iden et al. 2015; Rekawati et al. 2018).

> I tell myself that I mustn't be sad. I say a silent prayer. It makes me calm. (Iden et al. 2015)

5.6 Discussion

The aim of this metasynthesis was to describe how long-term care facilities influence the quality of life of their residents and to identify the similarities and differences between nursing homes and their alternatives in this respect. In a global context, however, there is no clear demarcation between these different kinds of facilities. Some assisted living facilities may have rather an institutional character and remind their residents to nursing homes and some nursing homes may have such a homelike atmosphere that they could be labelled as assisted living. The difference between concrete facilities as they are experienced by their residents seems to be only gradual. It may be more appropriate to consider both types of facilities as endpoints of a continuum of care that allows concrete facilities to be positioned according to their proximity to one of these two endpoints. At one end of this continuum, there are facilities that accommodate residents with less severe physical limitations who enjoy more independence. These residents tend to establish social contacts in the form of individual relationships and group building that include some of their roommates and exclude others. Within a system where such facilities are a preliminary stage to facilities for a higher level of care dependency, the independence of the residents is, however, under threat as they are constantly monitored with regard to their fitness and may be transferred to a nursing home in case they should fail to meet the criteria to stay.

At the other end of this continuum there are facilities to meet higher levels of care dependency. The restricted self-reliance of their residents can be associated with severe loss of choice and control. Residents are subjected to routines of care and live in a forced community where they tend to retreat into silence. Their lives seem to be reduced to sheer physical existence and they suffer from a loss of purpose in life. In countries, where no distinction between levels of institutional care exists, facilities may accommodate residents with all degrees of care dependency, but a policy that aims to delay or prevent admission to long-term care facilities can turn nursing homes into places where persons with the highest level of care dependency are concentrated. Since quality of life depends to some extent on the physical condition, it is under such circumstances not surprising that facilities for lower levels of care needs seem to ensure a higher level of quality of life.

It is, however, doubtful that such differences in quality of life can be captured by an objective measurement. The findings of this metasynthesis indicate that older persons tend to reduce unmet needs and compensate them by others in order to maintain their inner balance. Hence, unfavourable conditions do not necessarily affect their perceived satisfaction of needs. Attempts to measure quality of life aim to identify deficiencies that should be remedied. They may create awareness for a loss of quality of life that older persons have compensated by a change of attitudes and needs. Unintentionally, such measurements counteract these attempts to maintain the subjectively perceived quality of life. It is therefore not surprising that study participants tend to depict their own condition in a positive way. In other words, their responses may be biased, since such bias helps to maintain their quality of life. Ignoring deficiencies corresponds to the tendency to obtain a positive self-image and to deny adversities which are both orientations of action of every human being. Consequently, there is no quality of life as such that could be adequately measured if one would succeed in avoiding bias. Bias cannot be removed since it is an essential aspect of being a person and of every person's quest for quality of life. In part, quality of life results from a self-perception where the needs are adapted to the conditions of life. This does, however, not mean that such self-perception produces a stable state of well-being. Well-being is rather a fragile condition. It results from an inner balance of the opposite orientations of action that can be easily disturbed by external circumstances such as the loss of health or old home. Older persons than have to struggle to overcome these losses and to regain an inner balance. Such disturbances of the inner balance cannot be captured by a fast assessment, but they can be observed by caregivers if they engage in an individual care relationship that is based on trust and allows intimate knowledge of the care recipient. In other words, person-centred care is the way to recognize disturbances in quality of life with the aim of enabling older persons to overcome them.

The attempt of this metasynthesis was to identify the orientations of action that are of importance for the inner balance of older persons. It has of course some limitations. To some extent, the distinction between the different orientations of action remains vague. On the one hand, this is due to the fact that the different orientations of action affect each other. Thus, for example, the satisfaction of being cared for also conveys a certain feeling of closeness, or the satisfaction of self-reliance also promotes a sense of control and a positive self-image. In addition, orientations of action can often only be identified by the behaviour of residents. A particular behaviour, however, can serve several needs. Reading, for example, can meet the desire for diversion or reflection, depending on the kind of literature. Unfortunately, many of the investigated studies just listed a variety of behaviours and activities without specifying the underlying needs. In such cases, the interpretation had to rely on assumptions, which were of course prone to errors.

Some orientations of action may have been inappropriately understood or some may even be missing. For example, one would have expected to find a desire for creativity that was counterbalanced by an orientation towards destruction. The investigated data, however, did not justify the identification of these orientations of action. Since their existence is at least plausible, one has to assume that the model derived from this metasynthesis is still preliminary. Likewise, the needs for elimination and protection of body temperature, which play a role in everyday nursing practice, were not mentioned in any study. One reason might be that for the residents the issue of elimination is related to feelings of shame, and hence, they avoid mentioning this issue. In contrast to this, caregivers expect to hear about it since they have been trained to focus on possible problems in this area. The regulation of body temperature may not have been mentioned since residents did not perceive this to be any problem.

Moreover, the findings of this metasynthesis mainly apply to residents without cognitive impairments, since persons who suffer from dementia have only limited abilities to provide a clear idea of their needs. What matters to them has to be reconstructed by observations and remains necessarily fragmentary. The findings of this metasynthesis, however, may serve as a framework to understand also the concerns of those who cannot speak for themselves. They offer an orientation scheme for the assessment of their personality, and even if an understanding is doomed to remain fragmentary and incomplete, it is still a step forward in identifying and responding to their needs.

5.7 Conclusion

In summary, quality of life in long-term care facilities seems to be ambivalent. On the one hand, facilities can promote a feeling of safety and being cared for. Relieved from the burden of self-care, older persons can even enjoy a sense of independence as they can focus on activities that are more important to them. Living together with peers may also promote social contacts, which are a source of entertainment and an opportunity to find acknowledgement from others. Staying in a care facility may allow them to discover new perspectives and to find new hope. On the other hand, routines of care and rules of social life may result in a loss of self-reliance and control over one’s life with ensuing feelings of powerlessness, boredom, and a loss of self-esteem. As a consequence, admission to a long-term care facility may result in a serious crisis—especially if older persons are forced to move in against their will. They can feel cut off from the past and lose hope, which ultimately reduces the will to live on. Although many studies confirm this rather negative picture, the findings also provide opposite examples. Long-term care facilities can prevent but also promote the satisfaction of older persons’ orientations of action. Table 5.7 summarizes the key points of these findings.

Whether quality of life after admission to a long-term care facility develops in a positive or a negative way depends on a variety of factors. Most important seem to be the older persons’ physical condition, the influence they can exert on the decision to move in, the support they receive from family and friends, their attitude to life in general, and of course the care they receive in the facility. The investigated studies describe a variety of care interventions that may have an either positive or negative impact. However, there is no care that is always appropriate. Well intended actions may counteract the needs of residents if the focus of their orientations of action is on the opposite. Providing personal care may produce a feeling of being cared for, but can also result in a loss of self-reliance. Enforcing self-reliance by refusing to help can on the other hand produce feelings of being neglected. The company of

Table 5.7 Long-term care facilities and satisfaction of the orientations of action

Body-related orientations of action	
Physical activity *Satisfied* if residents maintain and enjoy mobility according to their capacities *Not satisfied* if residents have no opportunities for physical activity and experience a decline of mobility	*Physical rest* *Satisfied* if residents can have a rest and nap *Not satisfied* if residents suffer from sleep disorders or overexertion from physical activities
Body protection and regeneration *Satisfied* if residents experience physical wellness through receiving personal care *Not satisfied* if residents experience injuries, pain, and a decline of health	*Negligence towards health* *Satisfied* if residents are allowed to reduce hygiene and health care according to their needs *Not satisfied* if residents feel inconvenient due to exaggerated care for their health
Food consumption *Satisfied* if residents enjoy their meals *Not satisfied* if residents remain hungry or dislike the taste of food	*Food abstinence* *Satisfied* if residents could avoid satiety *Not satisfied* if residents suffered from satiety since they felt obliged to empty their plates
Sexual desire *Satisfied* if residents had sexual pleasure that was not disturbed by others *Not satisfied* if residents experienced sexual frustration due to lack of privacy or appropriate partners	*Sexual abstinence* *Satisfied* if residents remained undisturbed from sexual desires of others *Not satisfied* if residents experienced sexual harassment or marital rape
Social orientations of action	
Self-reliance *Satisfied* if residents maintain self-reliance *Not satisfied* if residents feel incapacitated by overprotective care and gradually lose their abilities	*Being cared for* *Satisfied* if residents feel comfort and relief of burden since caregivers are attentive to their needs and provide little extras *Not satisfied* if residents feel neglected, have to wait to get desired help
Exerting influence on others *Satisfied* if residents have choices and can participate in decisions about their own care *Not satisfied* if residents feel powerless since they had to move in against their own will, feel subjected to routines of care, and are annoyed by their roommates	*Attention to the needs of others* *Satisfied* if residents feel that they are no burden to their family and their caregivers *Not satisfied* if residents feel to be a burden to their family and their caregivers
Social adjustment *Satisfied* if residents feel normal and in tune with their social environment *Not satisfied* if residents feel shame for failures to meet social standards	*Unconventionality* *Satisfied* if residents can be spontaneous and feel unrestrained by social norms *Not satisfied* if residents have to suppress own needs
Closeness *Satisfied* if residents gain social contacts in the facility and maintain contacts to family and friends *Not satisfied* if residents lose old contacts and find no suitable person to talk to in the facility	*Distance* *Satisfied* if residents have their own room and others respect their privacy *Not satisfied* if residents stay in shared rooms and lack privacy

Table 5.7 (continued)

Identity-related orientations of action	
Work *Satisfied* if residents enjoy to be active and productive *Not satisfied* if residents have nothing to do to fill their time	*Relaxation* *Satisfied* if residents find mental relaxation *Not satisfied* if residents feel exposed to overburdening activities
Reflection *Satisfied* if residents find intellectual pleasure *Not satisfied* if residents are displeased by trivial entertainment and superficial conversation	*Diversion* *Satisfied* if residents feel entertained through social activities, music, or excursions *Not satisfied* if residents lack entertainment and stimulation
Self-centredness *Satisfied* if residents were able to meet their own interests by being in command, getting attention from others, and having their own pleasure *Not satisfied* if residents suffer from self-neglect	*Concern for others* *Satisfied* if residents have a feeling of being needed *Not satisfied* if residents feel useless and unable to reciprocate
Self-presentation *Satisfied* if residents attract the attention of others and are appreciated and respected by others *Not satisfied* if residents were not respected or ignored by others	*Self-concealment* *Satisfied* if residents remain unnoticed and undisturbed by undue attention of others *Not satisfied* if residents feel exposed to gossip and undue criticism of others
Positive self-perception *Satisfied* if residents have positive memories and were able to recognize their own strengths *Not satisfied* if residents have a negative self-image and were plagued by negative memories	*Critical self-perception* *Satisfied* if residents are able to recognize their weaknesses and to downsize their expectations *Not satisfied* if residents have no realistic idea about themselves and withdraw in an imaginary identity
Development-related orientations of action	
Attachment to the past *Satisfied* if residents find some continuity and experience a homelike atmosphere *Not satisfied* if residents suffer from the loss of their home and experience cultural alienation	*Searching new perspectives* *Satisfied* if residents discover a new life in the facility or develop a new sense of belonging *Not satisfied* if residents experience stagnation
Denial of adversities *Satisfied* if residents can live with undue worries and fears *Not satisfied* if residents suffer from fear due to their confrontation with death	*Facing adversities* *Satisfied* if residents are aware of and feel enabled to confront their approaching death *Not satisfied* if residents are not aware of their approaching death
Hope *Satisfied* if residents are enabled to enjoy the moment and to find religious comfort *Not satisfied* if residents resign and become hopeless	*Scepticism* *Satisfied* if residents are aware of their situation and adapt gradually *Not satisfied* if residents are attached to illusionary beliefs

roommates may promote social well-being but can also disrupt privacy. Too much privacy, however, can result in a lack of social contacts and loneliness. Joint activities may create diversion but can also produce feelings of triviality. Lack of diversion, on the other hand, may result in boredom. The list of examples could be extended further. It shows that care has to be adapted to the individual inclinations of the residents. For this reason, the findings of this metasynthesis do not allow establishing a fixed standard for appropriate care. They highlight, however, some principles of central importance that need to be observed by caregivers since they represent the core of person-centred care.

- First of all, caregivers should establish a relationship of trust. Quite often they become a substitute for social contacts that have been lost. If residents find someone to turn to, it reduces their sense of loneliness and makes them feel at home. Since residents want continuity in care relationships, every one of them should find a reference person in the care team who is primarily responsible for meeting his or her needs. To establish trust, caregivers need to have communicative skills. These include the ability to small talk, which serves no purpose except entertainment. Establishing trust is not a task that can solved in a time- and cost-efficient manner. It rather takes time to be spent with the resident.
- In such a relationship of trust, caregivers should be attentive to unspoken needs, as residents often follow habits and routines that go unreflected and are therefore not expressed. Moreover, older persons will not always tell their conscious needs since persons do not like to disclose their inner world to everybody. Having secrets is an essential aspect of being a person. They belong to the private sphere, and their protection represents a dimension of quality of life. Caregivers must therefore carefully identify unspoken needs without violating privacy. Such attention will also enable them to better understand the needs of those who cannot speak for themselves—even if only approximately.
- When caregivers enter in a dialogue with residents, active listening is of central importance. It enables residents to recognize their current resources and needs and to reflect on their biography. Reminiscence may allow them to gain self-acceptance by rediscovering their own strengths and to maintain a connection to their past.
- Active listening is also the way to learn about the residents' own concerns. Instead of identifying deficits according to some predetermined standards, caregivers should become aware of what really matters to the older persons. They should not determine what residents should achieve, but understand what residents want to achieve, since this enables them to be self-determined and to unfold their personality.
- Finally, to ensure self-determination, residents should be allowed to participate in the planning of their care and to have choices. In this way they can maintain a sense of control despite their loss of abilities and self-reliance.

Of course, it will be impossible to meet this ideal at all times. Individual interests must sometimes be neglected since caregivers have to meet the needs of more than one care recipient. Furthermore, residents must adapt to some extent to the rules of the community to which they belong. It seems, however, that in many facilities incidences that contradict this ideal are not the exception to the rules of person-centredness. The dominant understanding of care that exists in long-term care facilities rather disregards this idea. Care is mainly understood to be manual work which serves to produce some specified outcomes in a fast and effective way. Within such a framework of task-orientation, communication and active listening are not perceived to be interventions, since they show no immediate and measurable results. They rather seem to be an end in themselves and therefore without real value. However, quality of life is not a product that can be fabricated in a working process. A balanced satisfaction of orientations of actions emerges from within the individual and caregivers have to work like gardeners who can stimulate but not enforce the growth of plants. Such an enabling care would meet the needs of care recipients, but it requires that caregivers gain a new understanding of their own work. The understanding of care, however, depends not only on the individual caregiver but also on the social system in which they work. Therefore, it seems necessary to develop a new nursing culture that is focused on listening and dialogue if residents in long-term care facilities shall receive person-centred care.

References

Adra MG, Hopton J, Keady J (2015) Constructing the meaning of quality of life for residents in care homes in the Lebanon: perspectives of residents, staff and family. Int J Older People Nursing 10:306–318

Al-Omari H, Kramer K, Hronek C, Rempusheski VF (2005) The Wheat Valley assisted living culture: rituals and rules. J Gerontol Nurs 31(1):9–16

Andersson I, Pettersson E, Sidenvall B (2007) Daily life after moving into a care home--experiences from older people, relatives and contact persons. J Clin Nurs 16:1712–1718

Andrew A, Wilson LH (2014) A café on the premises of an aged care facility: more than just froth? Scand J Occup Ther 21:219–226

Andrews RA (2012) Anglo-Indian residential care homes: accounts from Kolkata and Melbourne. J Cross Cult Gerontol 27:79–100

Annerstedt L (1997) Group Living Care: an alternative for the demented elderly. Dement Geriatr Cogn Disord 8:136–142

Assisted Living Workgroup (2003) Assuring quality in assisted living: guidelines for federal and state policy, state regulation, and operations. Assisted Living Workgroup, Washington, DC

Ball MM, Whittington FJ, Perkins MM, Patterson VL, Hollingsworth C, King SV, Combs BL (2000) Quality of life in assisted living facilities: viewpoints of residents. J Appl Gerontol 19(3):304–325

Ball MM, Perkins MM, Whittington FJ, Connell BR, Hollingsworth C, King SV (2004a) Managing decline in assisted living: the key to aging in place. J Gerontol B Psychol Sci Soc Sci 59(4):202–212

Ball MM, Perkins MM, Whittington FJ, Hollingsworth C, King SV, Combs BL (2004b) Independence in assisted living. J Aging Stud 18(4):467–483

Ball MM, Lepore ML, Perkins MM, Hollingsworth C, Sweatman M (2009) “They are the reason I come to work”: the meaning of resident-staff relationships in assisted living. J Aging Stud 23(1):37–47

Barnes S, Wasielewska A, Raiswell C, Drummond B (2013) Exploring the mealtime experience in residential care settings for older people: an observational study. Health Soc Care Community 21:442–450

Bauer M, Fetherstonhaugh D, Tarzia L, Nay R, Wellman D, Beattie E (2013) 'I always look under the bed for a man'. Needs and barriers to the expression of sexuality in residential aged care: the views of residents with and without dementia. Psychol Sex 4:296–309

Behr A, Meyer R, Holzhausen M, Kuhlmey A, Schenk L (2013) Die Intimsphäre: Eine wichtige Dimension der Lebensqualität von Pflegeheimbewohnern. Zeitschrift für Gerontologie und Geriatrie 46:639–644

Behr A, Meyer R, Holzhausen M, Kuhlmey A (2014) Lebensqualität und Gesundheit – Subjektive Perspektiven von selbstauskunftsfähigen Pflegeheimbewohnern – eine qualitative Studie. Pflege 27:369–380

Bennett CR, Frankowski AC, Rubinstein RL, Peeples AD, Perez R, Nemec M, Tucker GG (2015) Visitors and resident autonomy: spoken and unspoken rules in assisted living. Gerontologist 57(2):252–260

Bergland A, Kirkevold M (2006) Thriving in nursing homes in Norway: contributing aspects described by residents. Int J Nurs Stud 43:681–691

Bland M (2007) Betwixt and between: a critical ethnography of comfort in New Zealand residential aged care. J Clin Nurs 16:937–944

Boggatz T (2011) Growing old in Egypt. American University Press of Cairo, Cairo

Boggatz T, Tamer F, Mohammedin A, Dassen T (2009) Attitudes of Egyptian nursing home residents towards staying in a nursing home: a qualitative study. Int J Older People Nursing 4(4):242–253

Bollig G, Gjengedal E, Rosland JH (2016) Nothing to complain about? Residents' and relatives' views on a "good life" and ethical challenges in nursing homes. Nurs Ethics 23:142–153

Bourrett EM, Bernick LG, Cott AA, Kontos PC (2002) The meaning of mobility for residents and staff in long-term care facilities. J Aging Health 37:338–345

Bowers BJ, Nolet K (2014) Developing the green house nursing care team: variations on development and implementation. Gerontologist 54(Suppl 1):53–64

Bowers BJ, Fibich B, Jacobson N (2001) Care-as-service, care-as-relating, care-as-comfort: understanding nursing home residents' definitions of quality. Gerontologist 41:539–545

Bowers H, Clark A, Crosby G, Easterbrook L, Macadam A, MacDonald R, MacFarlane A, MacLean A, Patel M, Runnicles D, Oshinaike T, Smith C (2009) Older people's vision for long-term care. Joseph Rowntree Foundation, York. Available at: https://www.jrf.org.uk/report/older-peoples-vision-long-term-care

Bradshaw SA, Playford ED, Riazi A (2012) Living well in care homes: a systematic review of qualitative studies. Age Ageing 41:429–440

Bright L (2007) Quality of life in care homes. Help the Aged, London. https://doi.org/10.7748/nop.19.1.11.s14

Brownie S, Horstmanshof L (2012) Creating the conditions for self-fulfilment for aged care residents. Nurs Ethics 19:777–786

Canham SL, Battersby L, Fang ML, Sixsmith J, Woolrych R, Sixsmith A (2016) From familiar faces to family: staff and resident relationships in long-term care. J Aging Health 2:842–857. https://doi.org/10.1177/0898264316645550

Carder PC (2002) The social world of assisted living. J Aging Stud 16:1–18

Chang SJ (2013) Lived experiences of nursing home residents in Korea. Asian Nurs Res 7:83–90

Cheng Y, Rosenberg MW, Wang W, Yang L, Li H (2011) Aging, health and place in residential care facilities in Beijing, China. Soc Sci Med 72:365–372

Chin L, Quine S (2012) Common factors that enhance the quality of life for women living in their own homes or in aged care facilities. J Women Aging 24:269–279

Cho E, Kim H, Kim J, Lee K, Meghani SH, Chang SJ (2017) Older adult residents' perceptions of daily lives in nursing homes. J Nurs Scholarsh 49:1–9

Christov V (2016) Gemeinschaft und Schweigen im Pflegeheim. [Community and silence in the nursing home]. Frankfurt a.M.: Mabuse

Chuang Y-H, Abbey J (2009) The culture of a Taiwanese nursing home. J Clin Nurs 18:1640–1648

Chuang Y-H, Abbey JA, Yeh Y-C, Tseng I-J, Liu MF (2015) As they see it: a qualitative study of how older residents in nursing homes perceive their care needs. Collegian 22:43–51

Cohen-Mansfield J, Werner P, Weinfield M, Braun J, Kraft G, Gerber B, Willens S (1995) Autonomy for nursing home residents: the role of regulations. Behav Sci Law 13:415–423

Cooney A (2011) ‘Finding home’: a grounded theory on how older people ‘find home’ in long-term care settings. Int J Older People Nursing 7:188–199

Cooney A, Murphy K, O’Shea E (2009) Resident perspectives of the determinants of quality of life in residential care in Ireland. J Adv Nurs 65:1029–1038

Coughlan R, Ward L (2007) Experiences of recently relocated residents of a long-term care facility in Ontario: assessing quality qualitatively. Int J Nurs Stud 44:47–57

Curle L, Keller H (2010) Resident interactions at mealtime: an exploratory study. Eur J Ageing 7:189–200

Dobbs D (2004) The adjustment to a new home. J Hous Elder 18:51–71

Dobbs D, Eckert JK, Rubinstein B, Keimig L, Clark L, Frankowski AC, Zimmerman S (2008) An ethnographic study of stigma and ageism in residential care or assisted living. Gerontologist 48:517–526

Donaldson WV, Asta EL, Vacha-Haase T (2014) Attitudes of heterosexual assisted living residents toward gay and lesbian peers. Clin Gerontol 37:167–189

Donnelly L, MacEntee MI (2016) Care perceptions among residents of LTC facilities purporting to offer person-centred care. Can J Aging 35:149–160

Eckert JK, Carder PC, Morgan LA, Frankowski AC, Roth E (2009) Inside assisted living: the search for home. The John Hopkins University Press, Baltimore

Eika M, Dale B, Espnes GA, Hvalvik S (2015) Nursing staff interactions during the older residents’ transition into long-term care facility in a nursing home in rural Norway: an ethnographic study. BMC Health Serv Res 15:125. https://doi.org/10.1186/s12913-015-0818-z

Falk H, Wijk H, Persson LO, Falk K (2013) A sense of home in residential care. Scand J Caring Sci 27:999–1009

Figueredo-Borda N, Zabalegui-Yárnoz A (2015) Long-term care of the elderly in uruguay. J Transcult Nurs 26:178–184

Fiveash B (1998) The experience of nursing home life. Int J Nurs Pract 4:166–174

Fraher A, Coffey A (2011) Older people’s experiences of relocation to long-term care. Nurs Older People 23:23–27

Frankowski AC, Clark LJ (2009) Sexuality and intimacy in assisted living: residents’ perspectives and experiences. Sex Res Social Policy 6:25–37

Giarchi GG (2002) A conspectus of types, options and conditions of elder-accommodation in the European continent. Innovations 15(2):99–119

Goddard C, Speck P, Martin P, Hall S (2013) Dignity therapy for older people in care homes: a qualitative study of the views of residents and recipients of ‘generativity’ documents. J Adv Nurs 69:122–132

Grando VT, Mehr D, Popejoy L, Maas ML, Westhoff R (2000) Light care residents in nursing homes: why they come, why they stay. Nurs Adm Q 24:53–63

Grant NK, Reimer M, Bannatyne J (1996) Indicators of quality in long-term care facilities. Int J Nurs Stud 33:469–478

Grau L, Chandler B, Saunders C (1995) Nursing home residents’ perceptions of the quality of their care. J Psychosoc Nurs Ment Health Serv 33:34–41

Gubrium JF (1997) Living and dying at murray manor. University Press of Virginia, Charlottesville

Gustavsson M, Liedberg GM, Ranada ÅL (2015) Everyday doings in a nursing home – described by residents and staff. Scand J Occup Ther 22:435–441

Harmer BJ, Orrell M (2008) What is meaningful activity for people with dementia living in care homes? A comparison of the views of older people with dementia, staff and family carers. Aging Ment Health 12:548–558

Hauge S, Heggen K (2008) The nursing home as a home: a field study of residents’ daily life in the common living rooms. J Clin Nurs 17:460–467

Hawes C, Phillips CD, Rose M, Holan S, Sherman M (2003) A national survey of assisted living facilities. Gerontologist 43:875–882

Heid AR, Eshraghi K, Duntzee CI, Abbott K, Curyto K, van Haitsma K (2016) “It depends”: reasons why nursing home residents change their minds about care preferences. Gerontologist 56:243–255

Heliker D (2009) Enhancing relationships in long-term care through story sharing. J Gerontol Nurs 35:43–49

Heliker D, Scholler-Jaquish A (2006) Transition of new residents to long-term care: basing practice on residents’ perspective. J Gerontol Nurs 32:34–42

Hellström UW, Sarvimäki A (2007) Experiences of self-determination by older persons living in sheltered housing. Nurs Ethics 14:413–424

Herrmann WJ, Flick U (2011) Nursing home residents’ self-perceived resources for good sleep. Scand J Prim Health Care 29:247–251

Hillcoat-Nalletamby S (2014) The meaning of “independence” for older people in different residential settings. J Gerontol B Psychol Sci Soc Sci 69:419–430

Hinman MR, Heyl DM (2009) Influence of the Eden alternative™ on the functional status of nursing home residents. Phys Occup Ther Geriatr 20:1–20

Hjaltadóttir I, Gustafsdóttir M (2007) Quality of life in nursing homes: perception of physically frail elderly residents. Scand J Caring Sci 21:48–55

Holmberg MD, Flum M, West C, Zhang Y, Qamili S, Punnett L (2013) Nursing assistants’ dilemma: caregiver versus caretaker. Hosp Top 91:1–8

Holmgren J, Emami A, Eriksson LE, Eriksson H (2013) Being perceived as a ‘visitor’ in the nursing staff’s working arena - the involvement of relatives in daily caring activities in nursing homes in an urban community in Sweden. Scand J Caring Sci 27:677–685

Hubbard G, Tester S, Downs MG (2003) Meaningful social interactions between older people in institutional care settings. Ageing Soc 23:99–114

Hutchinson S, Hersch G, Davidson HA, Chu AY-M, Mastel-Smith B (2011) Voices of elders: culture and person factors of residents admitted to long-term care facilities. J Transcult Nurs 22:397–404

Hwang H-L, Hsieh P-F, Wang H-H (2013) Taiwanese long-term care facility residents’ experiences of caring: a qualitative study. Scand J Caring Sci 27:695–703

Hweidi I (1999) A Jordanian nursing home: an ethnographic study. The Catholic University of America, Washington DC

Iden KR, Ruths S, Hjørleifsson S (2015) Residents’ perceptions of their own sadness - a qualitative study in Norwegian nursing homes. BMC Geriatr 15:21

Iwasiw C, Goldenberg D, McCutcheon S, Bol N (1996) Residents’ perspectives of their first 2 weeks in a long-term care facility. J Clin Nurs 5:381–388

Iwasiw C, Goldenberg D, Bol N, McMaster E (2003) The first year in a long-term care facility. J Gerontol Nurs 29(1):45–54

James I, Blomberg K, Kihlgren A (2014) A meaningful daily life in nursing homes - a place of shelter and a space of freedom: a participatory appreciative action reflection study. BMC Nurs 13:19

Jordan LG (2010) The perceptions of nursing team caring behaviors among residents of an assisted living facility for retired veterans. Dissertation, The Catholic University of America, Washington, DC

Josat S (2005) Welche Qualitätskriterien sind Angehörigen in der stationären Altenpflege wichtig? Eine Einzelfallstudie. Pflege 18:169–175

Karlsson I, Ekman S-L, Fagerberg I (2009) A difficult mission to work as a nurse in a residential care home--some registered nurses’ experiences of their work situation. Scand J Caring Sci 23:265–273

Kemp CL (2008) Negotiating transitions in later life married couples in assisted living. J Appl Gerontol 27:231–251

Kemp CL, Ball MM, Hollingsworth C, Perkins MM (2012) Strangers and friends: residents’ social careers in assisted living. J Gerontol B Psychol Sci Soc Sci 67:491–502

Kemp CL, Ball MM, Perkins MM (2016) Couples' social careers in assisted living: reconciling individual and shared situations. Gerontologist 56:841–854

Kennedy D, Sylvia E, Bani-Issa W, Khater W, Forbes-Thompson S (2005) Beyond the rhythm and routine: adjusting to life in assisted living. J Gerontol Nurs 31:17–23

Kennemerhart (2018) Anton Piekhofje. Kennemerhart, Haarlem (online). Available at: https://www.kennemerhart.nl/locaties/woonzorgcentrum-anton-pieckhofje-haarlem/

Koch-Straube U (2003) Fremde Welt Pflegeheim. Huber, Bern

Koppitz AL, Dreizler J, Altherr J, Bosshard G, Naef R, Imhof L (2017) Relocation experiences with unplanned admission to a nursing home: a qualitative study. Int Psychogeriatr 29:517–527

Koskenniemi J, Leino-Kilpi H, Suhonen R (2015) Manifestation of respect in the care of older patients in long-term care settings. Scand J Caring Sci 29:288–296

Kuhn MG (2008) The eye of beauty: creating a place for elite and aging elders. Dissertation, The University of Arizona, Tucson

Lung C-C, Liu JYW (2016) How the perspectives of nursing assistants and frail elderly residents on their daily interaction in nursing homes affect their interaction: a qualitative study. BMC Geriatr 16:13

Mahrs Träff A, Cedersund E, Nord C (2017) Perceptions of physical activity among elderly residents and professionals in assisted living facilities. Eur Rev Aging Phys Act 14:2. https://doi.org/10.1186/s11556-017-0171-9

Martinsson I, Edberg A-K, Janlöv A-C (2013) Growing old in a foreign context -- older immigrants' experience of everyday life in residential care facilities. Nordic J Nurs Res Clin Stud 33:34–38

Melin-Johansson C, Eriksson U, Segerback I, Bostrom S (2014) Reflections of older people living in nursing homes. Nurs Older People 26:33–39

Minney MJ, Ranzijn R (2016) "We had a beautiful home … but I think I'm happier here": a good or better life in residential aged care. Gerontologist 56:919–927

Mohammadinia N, Rezaei MA, Atashzadeh-Shoorideh F (2017) Elderly peoples' experiences of nursing homes in Bam city: a qualitative study. Electron Physician 9:5015–5023

Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med, 6(7), e1000097

Murphy K (2007) A qualitative study explaining nurses' perceptions of quality care for older people in long-term care settings in Ireland. J Clin Nurs 16:477–485

Murphy K, Shea EO, Cooney A (2007) Quality of life for older people living in long-stay settings in Ireland. J Clin Nurs 16:2167–2177

Naess A, Fjaer EG, Vabo M (2016) The assisted presentations of self in nursing home life. Soc Sci Med 150:153–159

Nakrem S (2015) Understanding organizational and cultural premises for quality of care in nursing homes: an ethnographic study. BMC Health Serv Res 15:508. https://doi.org/10.1186/s12913-015-1171-y

Nakrem S, Vinsnes AG, Seim A (2011) Residents' experiences of interpersonal factors in nursing home care: a qualitative study. Int J Nurs Stud 48:1357–1366

Nakrem S, Vinsnes AG, Harkless GE, Paulsen B, Seim A (2013) Ambiguities: residents' experience of 'nursing home as my home'. Int J Older People Nursing 8:216–225

Nay R (1992) Sexuality and aged women in nursing homes. Geriatr Nurs 13:312–314

Nord C (2013) A day to be lived: elderly peoples' possessions for everyday life in assisted living. J Aging Stud 27:135–142

O'Shea F, Weathers E, McCarthy G (2014) Family care experiences in nursing home facilities. Nurs Older People 26:26–31

Oakes CE, Sheehan NW (2012) Autonomy in assisted living: employees' perspectives. J Hous Elder 26:317–337

Oosterveld-Vlug MG, Pasman HRW, van Gennip IE, Willems DL, Onwuteaka-Philipsen BD (2013a) Changes in the personal dignity of nursing home residents: a longitudinal qualitative interview study. PLoS One 8:e73822

Oosterveld-Vlug MG, Pasman HRW, van Gennip IE, Willems DL, Onwuteaka-Philipsen BD (2013b) Nursing home staff's views on residents' dignity: a qualitative interview study. BMC Health Serv Res 13:353

Oosterveld-Vlug MG, Pasman HRW, van Gennip IE, Muller MT, Willems DL, Onwuteaka-Philipsen BD (2014) Dignity and the factors that influence it according to nursing home residents: a qualitative interview study. J Adv Nurs 70:97–106

Palacios-Ceña D, Losa-Iglesias ME, Cachon-Perez JM, Gomez-Perez D, Gomez-Calero C, Fernandez-de-las-Penas C (2013) Is the mealtime experience in nursing homes understood? A qualitative study. Geriatr Gerontol Int 13:482–489

Palacios-Ceña D, Gómez-Calero C, Cachón-Pérez JM, Velarde-García JF, Martínez-Piedrola R, Pérez-De-Heredia M (2016a) Is the experience of meaningful activities understood in nursing homes? A qualitative study. Geriatr Nurs 37:110–115

Palacios-Ceña D, Martínez-Piedrola RM, Pérez-De-Heredia M, Huertas-Hoyas E, Carrasco-Garrido P, Fernández-de-Las-Peñas C (2016b) Expressing sexuality in nursing homes The experience of older women: a qualitative study. Geriatr Nurs 37:470–477

Pannell J, Blood I (2012) Supported housing for older people in the UK: an evidence review. Online available at: https://www.jrf.org.uk/sites/default/files/jrf/migrated/files/sheltered-retirement-housing-full.pdf. Accessed 01 Aug 2016

Park NS, Knapp MA, Shin HJ, Kinslow KM (2009) Mixed methods study of social engagement in assisted living communities: challenges and implications for serving older men. J Gerontol Soc Work 52:767–783

Park NS, Zimmerman S, Kinslow K, Shin HJ, Roff LL (2012) Social engagement in assisted living and implications for practice. J Appl Gerontol 31:215–238

Park NS, Dobbs D, Carrion IV, Young TL, Salmon JR, Roff LL (2013) Social relationships of African American and hispanic older assisted living residents: exploring the role of race and ethnicity. J Hous Elder 27:369–391

Perkins MM, Ball MM, Whittington FJ, Hollingsworth C (2012) Relational autonomy in assisted living: a focus on diverse care settings for older adults. J Aging Stud 26:214–225

Perkins MM, Ball MM, Kemp CL, Hollingsworth C (2013) Social relations and resident health in assisted living: an application of the convoy model. Gerontologist 53:495–507

Philpin S, Merrell J, Warring J, Gregory V, Hobby D (2011) Sociocultural context of nutrition in care homes. Nurs Older People 23:24–30

Pryce H, Gooberman-Hill R (2012) There's a hell of a noise: living with a hearing loss in residential care. Age Ageing 41:40–46

Rabig J, Thomas W, Kane RA, Cutler LJ, McAlilly S (2006) Radical redesign of nursing homes: applying the green house concept in Tupelo, Mississippi. Gerontologist 46:533–539

Rahayu S, Catharina Daulima NH, Eka Putri YS (2018) The experience of older people living in an elderly residential home (Panti Sosial Tresna Werdha): a phenomenology. Enferm Clin 28:79–82

Raske M (2010) Nursing home quality of life: study of an enabling garden. J Gerontol Soc Work 53:336–351

Rekawati E, Sahar J, Widyatuti, Abas I, Chaidir (2018) The experience of older people living in nursing home (Panti Wredha) in DKI Jakarta, Indonesia. Enferm Clin 28:347–352

Roberts T, Bowers B (2015) How nursing home residents develop relationships with peers and staff: a grounded theory study. Int J Nurs Stud 52:57–67

Robichaud L, Durand PJ, Bédard R, Ouellet J-P (2006) Quality of life indicators in long-term care: opinions of elderly residents and their families. Can J Occup Ther 73:245–251

Rossen EK, Knafl KA (2003) Older women's response to residential relocation: description of transition styles. Qual Health Res 13:20–36

Rugh AB (1981) Orphanages and homes for the aged in Egypt: contradiction or affirmation in a family oriented society. Int J Sociol Fam 11(2):203–233

Sandhu NK, Kemp CL, Ball MM, Burgess EO, Perkins MM (2013) Coming together and pulling apart: exploring the influence of functional status on co-resident relationships in assisted living. J Aging Stud 27:317–329

Saunders JC, Heliker D (2008) Lessons learned from 5 women as they transition into assisted living. Geriatr Nurs 29:369–375

Schenk L, Meyer R, Behr A, Kuhlmey A, Holzhausen M (2013) Quality of life in nursing homes: results of a qualitative resident survey. Qual Life Res 22:2929–2938

Shaw RL, West K, Hagger B, Holland CA (2016) Living well to the end: a phenomenological analysis of life in extra care housing. Int J Qual Stud Health Well-being 11:31100

Shin D (2008) Residential and caregiver preferences of older Korean Americans. J Gerontol Nurs 34:48–54

Shin J-H (2015) Declining body, institutional life, and making home-are they at odds? The lived experiences of moving through staged care in long-term care settings. HEC Forum 27:107–125

Shippee TP (2009) "But I am not moving": residents' perspectives on transitions within a continuing care retirement community. Gerontologist 49:418–427

Shrestha S, Zarit SH (2012) Cultural and contextual analysis of quality of life among older Nepali women. J Cross Cult Gerontol 27:163–182

Sidenvall B (1999) Meal procedures in institutions for elderly people: a theoretical interpretation. J Adv Nurs 30:319–328

Sidenvall B, Fjellström C, Ek AC (1994) The meal situation in geriatric care - intentions and experiences. J Adv Nurs 20:613–621

Simon A, Berwig M, Heinrich S (2013) Quality of life in nursing homes following the group-living principle: a pilot study measuring the quality of life from the subjective perspective of dependent-living elderly. Zeitschrift fur Gerontologie und Geriatrie 46:556–562

Slettebo A, Saeteren B, Caspari S, Lohne V, Rehnsfeldt AW, Heggestad AKT, Lillesto B, Hoy B, Raholm M-B, Lindwall L, Aasgaard T, Naden D (2016) The significance of meaningful and enjoyable activities for nursing home resident's experiences of dignity. Scand J Caring Sci 31:718–726

Speller B, Stolee P (2015) Client safety in assisted living: perspectives from clients, personal support workers and administrative staff in Toronto, Canada. Health Soc Care Community 23:131–140

Stathi A, Simey P (2007) Quality of life in the fourth age: exercise experiences of nursing home residents. J Aging Phys Act 15:272–286

Stevens AK, Raphael H, Green SM (2015) A qualitative study of older people with minimal care needs experiences of their admission to a nursing home with Registered Nurse care. Qual Ageing Older Adults 16:94–105

Svidén G, Wikström B-M, Hjortsjö-Norberg M (2009) Elderly persons' reflections on relocating to living at sheltered housing. Scand J Occup Ther 9:10–16

Taylor J, Sims J, Haines TP (2014) 'I accept it staff assistance; no choice': an ethnographic study of residents' attitudes towards mobility within nursing homes. Int J Older People Nursing 9:258–268

Teka A, Adamek ME (2014) "We prefer greeting rather than eating:" life in an elder care center in Ethiopia. J Cross Cult Gerontol 29:389–404

Thomas JE, O'Connell B, Gaskin CJ (2013) Residents' perceptions and experiences of social interaction and participation in leisure activities in residential aged care. Contemp Nurse 45:244–254

Timonen V, O'Dwyer C (2009) Living in institutional care: residents' experiences and coping strategies. Soc Work Health Care 48:1–27

Tompkins CJ, Ihara ES, Cusick A, Park NS (2012) "Maintaining connections but wanting more": the continuity of familial relationships among assisted-living residents. J Gerontol Soc Work 55:249–261

Tsai H-H, Tsai Y-F (2008) A temporary home to nurture health: lived experiences of older nursing home residents in Taiwan. J Clin Nurs 17:1915–1922

Tucket AG (2007) The meaning of nursing-home: 'Waiting to go up to St. Peter, OK! Waiting house, sad but true' - An Australian perspective. J Aging Stud 21:119–133

Tuominen L, Leino-Kilpi H, Suhonen R (2016) Older people's experiences of their free will in nursing homes. Nurs Ethics 23:22–35

Twenhöfel R (2007) Die Altenpflege im Zugriff der Disziplinen. Paradoxien und Perspektiven. Pflege und Gesellschaft 3:210–226

Villar F, Celdrán M, Fabà J, Serrat R (2014) Barriers to sexual expression in residential aged care facilities (RACFs): comparison of staff and residents' views. J Adv Nurs 70:2518–2527

Walker CA, Curry IC, Hogstel MO (2007) Relocation stress syndrome in older adults transitioning from home to a long-term care facility: myth or reality? J Psychosoc Nurs Ment Health Serv 45:38–47

Walker H, Paliadelis P (2016) Older peoples' experiences of living in a residential aged care facility in Australia. Australas J Ageing 35:E6–E10

Warren CAB, Williams KN (2008) Interviewing elderly residents in assisted living. Qual Sociol 31:407–424

Westin L, Danielson E (2007) Encounters in Swedish nursing homes: a hermeneutic study of residents' experiences. J Adv Nurs 60:172–180

Williams KN, Warren CAB (2008) Assisted living and the aging trajectory. J Women Aging 20:309–327

Williams KN, Warren CAB (2009) Communication in assisted living. J Aging Stud 23:24–36

Wilson KB (2007) Historical evolution of assisted living in the United States, 1979 to the present. Gerontologist 47:8–22

Wilson CB, Davies S (2009) Developing relationships in long term care environments: the contribution of staff. J Clin Nurs 18:1746–1755

Wright F, Tinker A, Mayagoitia R, Hanson J, Wojgani H, Holmans A (2010) What is the 'extra' in extra care housing? Br J Soc Work 40:2239–2254

Wu S, Barker JC (2008) Hot tea and juk: the institutional meaning of food for Chinese elders in an American nursing home. J Gerontol Nurs 34:46–54

Wu S-C, White A, Cash K, Foster S (2009) Nursing home care for older people in Taiwan: a process of forced choice. J Clin Nurs 18:1986–1993

Zimmerman S, Cohen LW (2010) Evidence behind the Green House and similar models of nursing home care. Aging Health 6:717–737

Zimmerman S, Sloane PD (2007) Definition and classification of assisted living. Gerontologist 47:33–39

Zimmerman S, Dobbs D, Roth EG, Goldman S, Peeples AD, Wallace B (2016) Promoting and protecting against stigma in assisted living and nursing homes. Gerontologist 56:535–547

6 Quality of Life in the Process of Dying

6.1 Care and the Process of Dying

6.1.1 The Process of Dying

Death is the unavoidable end of life. Every human being has to undergo the process of dying. When people die young, this is experienced as particularly dramatic. All their hopes and life plans are destroyed and come to a sudden end. Such a death prevents the accomplishment of life. When people die old, however, one is inclined to assume that they have completed their life and therefore death is perceived to be a natural event. This is of course just the common idea of death in old age and it does not tell anything about how older persons experience their process of dying.

In her meanwhile classical book “On Death and Dying” Elisabeth Kübler-Ross (2014) distinguishes five stages in the process of dying. When patients come to know that they are suffering from an incurable disease their first reaction consists of shock and then denial. After some time they may realize that such denial is futile and respond with anger. They become nasty, demanding and critical and blame those who try to help them for having their disease. If they find that such anger is in vain, they reach the next stage where they try to bargain in order to extend their life at least for some period of time. Since such bargaining only yields a momentary gain, but never restores their lives, they eventually become depressed. This depression is not a pathologic disorder but a normal reaction to realizing that one is losing one’s life. It is a preparatory grief over impending loss and the patients begin to separate from the people they have to leave in the near future. If they are allowed to express their rage and their depression while going through the respective stages they may finally reach the stage of acceptance. According to Kübler-Ross, such acceptance is not resignation due to defeat; it is rather beyond any affect and patients may say that their time has come and that this is all right. All stages of this process are accompanied by the hope of healing. In sum, the process of dying as described by Kübler-Ross seems to be a struggle to survive that is gradually lost until the dying person gives in and is ready to go.

T. Boggatz, *Quality of Life and Person-Centered Care for Older People*,
https://doi.org/10.1007/978-3-030-29990-3_6

There is, however, not only one kind of dying process. Life-threatening diseases may have different trajectories that influence the experience of dying. The trajectory of cancer that underlies the process of dying as described by Kübler-Ross (2014) consists of "a long period of functional stability… followed by a relatively brief and predictable course of decline that usually lasts less than 6 weeks" (Skolnick 1998). According to Ball et al. (2014), who investigated the process of dying in assisted living, only 14% of the observed cases had such a trajectory. In contrast to death caused by cancer, the trajectory of a congestive heart failure is marked by a rather steady decline (Skolnick 1998). This trajectory seems to be more common among older persons. According to the study of Ball et al. (2014), 61% of the cases experienced such a gradual decline associated with advanced age and chronic illness. Furthermore, sudden deaths may occur. Ball et al. found that 25% of the observed cases corresponded to such a death from an acute health episode.

These different trajectories influence how the dying person and her social environment can react to the dying process. As there is not always a clear indication of its beginning, the question of whether someone is dying is in part a matter of definition. If death occurs suddenly, neither patient nor doctor or nurses may be able to foresee its occurrence. There is no time for a debate between both sides as to whether or not dying takes place. Barclay et al. (2014) who investigated dying trajectories in nursing homes labelled this process as "unexpected dying" since death occurred suddenly in the care facility. Similar cases were "unpredictable dying" where an unexpected event like a fall led to hospital admission and subsequent inpatient death (ibid.).

If the process of dying is characterized by a slow and steady decline, it may be difficult to determine when someone is approaching his end and even if the person is severely disabled there are usually no physical events that would justify labelling them as dying (Skolnick 1998). As a consequence, there may be diagnostic uncertainty on the side of the medical staff that prevents a clear decision in favour of either curative, restorative, or palliative goals. If approaching death is only detected in the last hours or days of life, the possibilities of providing palliative care are restricted (Cable-Williams and Wilson 2014). Due to this uncertainty the dying person herself has no clear awareness of the living–dying interval, which has been defined as the time between the knowledge of the impending death and death itself (Engle et al. 1998).

Death may only be anticipated if the disease has a relatively clear prognosis as in the case of cancer. Glaser and Strauss (1968) found in their meanwhile classical study about dying in hospitals that the awareness of such a dying process may be different. In case of a closed awareness, patients are not aware of their own impending death and staff members try to conceal it by maintaining the fiction that the dying patient might recover. In suspicion awareness patients do not know for certain that they are dying but they suspect it and try to find out the truth that medical staff intends to hide from them. Mutual pretence occurs when both patient and medical staff know that the patient is dying, but both maintain the illusion that he might recover. Open awareness, finally, occurs when both sides acknowledge that the patient's condition is terminal. With a relatively clear diagnosis, the anticipation of death can therefore be one-sided or two-sided, and the kind of awareness that is permitted by the setting will influence the experience of dying and the decisions to be made regarding care and treatment.

6.1.2 Palliative Care and End-of-Life Care

When older persons are dying they obviously need to be cared for by others. With regard to such care one may distinguish between palliative care and end-of-life care. The WHO defines palliative care as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems" (WHO 2014). Dying is here regarded not as something to be avoided by treatment but as a normal process and palliative care neither hastens nor postpones death. It provides relief from pain and other distressing symptoms, integrates the psychological and spiritual aspects of patient care, offers a support system to help patients live as actively as possible until death, and early in the course of illness, it also includes therapies that are intended to prolong life, such as chemotherapy or radiation therapy, as well as investigations needed to better understand and manage distressing clinical complications. Whereas palliative care refers to a longer period of time, end-of-life care is directed towards the care of persons who are nearing end of life (Froggatt et al. 2006; Krau 2016). It can be seen as the last phase of palliative care where the focus is no longer on treatment but on allowing patients to die with dignity. Some authors (Krau 2016) define this period as the last six months of life the beginning of which, however, may be difficult to determine in advance due to the above-mentioned diagnostic uncertainty. Since a shift from curative to palliative end-of-life care requires an open awareness on the part of the dying person and his or her environment that death is approaching, diagnostic uncertainty may prevent the onset of palliative care.

Dying, palliative, and end-of-life care may occur in different settings. Some older persons die at home while receiving home care. Those who live in assisted living facilities or nursing homes may die in these places. Depending on the development of their condition and the available options of the health care system, older persons living at home or in a care facility may need temporarily treatment in a medical centre or clinic for the management of clinical symptoms and in case of an acute worsening of their condition they may finally be referred to a hospital and die on a regular ward. Several countries, however, made hospice care available for those who are dying. Hospices emerged in response to hospital care for the dying which was perceived as unsatisfactory, since hospital treatment focused mainly on curing diseases and was rather unable to recognize the needs of those who were incurable. In contrast to this, hospice care was meant to maintain or improve quality of life for those whose condition was unlikely to be cured and to provide palliative and end-of-life care (Hospice Foundation of America 2018). Nowadays, hospice care is provided in a wide range of settings, not just in hospice buildings. These include day care centres, specialized care homes, and people's own homes. The vast majority of hospice care is in fact provided in the homes of the dying persons (Hospice UK 2019). Hospice services may also be provided to persons who stay in long-term care facilities where regular care can be supplemented by specialized hospice nurses who regularly visit the facility and are in charge of drug administration, pain management, and skin integrity (Ball et al. 2014).

6.1.3 Advance Care Planning

The available options of care influence of course the way how the process of dying is experienced by older persons. Regardless of the setting where it takes place, palliative and end-of-life care involve decisions on the part of the dying persons—at least as long as they are able to make conscious decisions (Steinhauser et al. 2000). Dying persons have to decide whether and when they want to enrol in hospice care. Regardless of this decision, they have to formulate advance directives for their end-of-life care. These directives concern their desire for resuscitation, tube feeding, aggressive treatment through dialysis, pacemakers, medications (e.g. antibiotics), and if necessary hospitalization (Waldrop and Meeker 2014). Due to the possibilities of modern technology, older persons cannot avoid making such decisions—unless they want to leave them to the medical staff. Since, for ethical reasons, medical staff cannot make such decisions on behalf of those concerned, nowadays lawmakers in several countries insist that older persons make them in advance when they are still capable of doing so. In the USA, for example, the Patient Self-Determination Act of 1991 requires hospitals, skilled nursing facilities, and home health services to inquire, at admission, if patients or residents have in place advance directives and to provide them with a written summary of their rights in regard to health-related decision-making rights (van Leuven 2011). Due to such legislations, a new phase in the process of dying emerged that can be referred to as the hypothetical phase, since older people now have to think about their dying when the actual process has not yet begun and plan the desired care in advance. Quite often, however, older persons do not consider end-of-life care in advance, but only when the process of dying has already begun, so that a distinction between a phase of advance care planning and a phase of dying is not always possible.

An expert panel of the European Association for Palliative Care defined in a consensus advance care planning as a process that "enables individuals who have decisional capacity to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and health-care providers" (Rietjens et al. 2017, e546). Advance care planning may have one of the three following outcomes which for legal reasons should be recorded in writing:

- A living will which is a statement of wishes and values that spells out which medical treatments a person would like to receive and which not.
- An advance decision to refuse treatment, especially cardiopulmonary resuscitation also referred to as do-not-resuscitate order.
- A lasting power of attorney in which a person can name another person to make decisions on behalf of her when she is unable to do so.

For some older persons, however, an open discussion about care and treatment at the end of life is not restricted to the acceptance or rejection of life sustaining treatment. Rather, they want to determine time and manner of death by themselves and demand the right to commit suicide with the assistance of others. According to Broeckaert (2009) one may distinguish between a desire for voluntary euthanasia, which is "the intentional administration of lethal drugs in order to painlessly terminate the life of a patient suffering from an incurable condition deemed unbearable by the patient, at this patient's request," and a desire for assisted suicide, which means "intentionally assisting a person, at this person's request, to terminate his or her life" (ibid., p. 111). Some countries in Europe (Switzerland, Belgium, Luxembourg, and the Netherlands) and some states in the USA (Oregon, Washington State, Montana) have legalized physician-assisted suicide in unbearable sufferings and in a cultural climate that values self-determination, autonomy, and individualism there is also a growing minority that supports assisted suicide or auto-euthanasia when older persons do not suffer from a disease but are just tired of living (van Wijngaarden et al. 2015). In the previous chapter we encountered such older persons among the residents of long-terms care facilities and although they were unable to implement their desire they explicitly expressed a wish to die. A desire for auto-euthanasia, however, was not found among the dying persons that were interviewed by Kübler-Ross (2014). This attitude even contradicts her findings that describe the process of dying as a struggle against death. If there are, however, older persons who rather struggle for their right to die, the process of dying in old age may sometimes take a completely different course than it is known from the investigations of Kübler-Ross (2014).

6.1.4 Quality of Life and the Process of Dying

Given this background, the question that arises is how older persons experience their process of dying? How do they prepare themselves for this process when they are confronted with the question of advance care planning? And how do they deal with their dying when they are aware that the end of their life is approaching? In both situations, external circumstances and especially care are likely to influence their experiences. Therefore, the impact of these factors on quality of life in the process of dying should be explored in particular.

This chapter will try to answer these questions. Like the other chapters, it is based on an extensive literature research in the databases Pubmed, CINAHL, and Embase as shown in Fig. 6.1. Again, the research was restricted to studies published

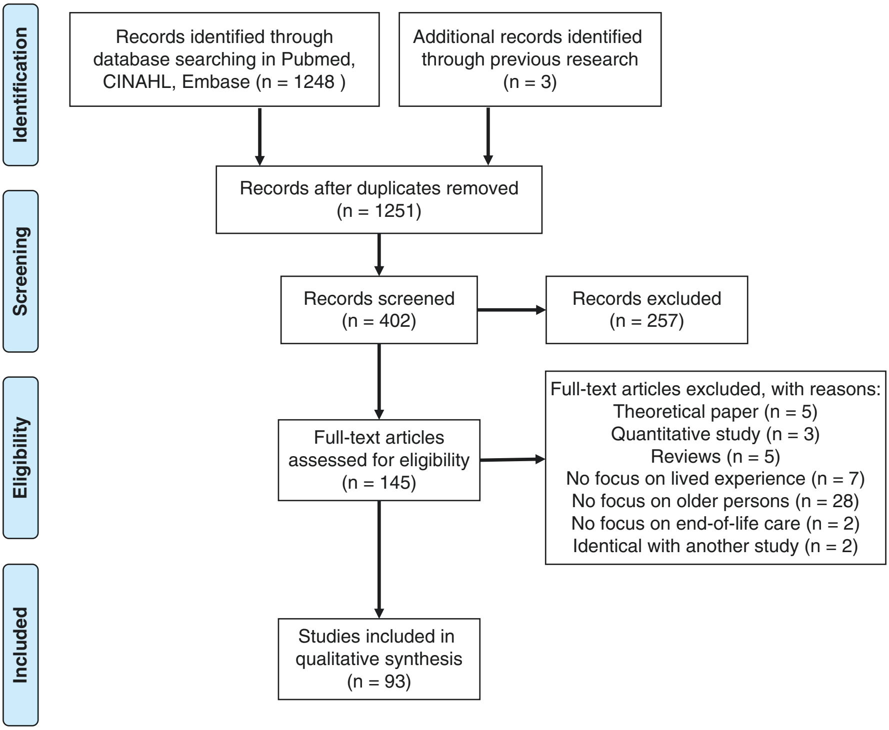

Fig. 6.1 Earch strategy according to PRISMA (Moher et al. 2009)

in either English or German that were not older than 20 years. Since dying occurs in different settings, all studies were included that investigated the process of dying from the perspective of older persons—regardless of where this happened. To understand their perspective when they have to consider the process of dying before it actually occurs, studies investigating the experience of advance care planning were also included. These also comprised studies about older persons' attitudes towards auto-euthanasia and assisted suicide. Only qualitative studies were eligible for evaluation. Participants had to be above 60 to capture the perspective of older persons. Unfortunately, many studies about the process of dying were not restricted to this age group and investigated also the experience of younger persons. Such studies were only included if the majority of the participants were above 60 and if it was discernible which statements and experiences were actually made by the older participants. In a similar way, studies that also reported about the perspective of staff or family members were included if it was clear which statement reflected the experience of the older persons themselves.

Altogether 93 studies were included. Table 6.1 provides an overview over the countries where they were performed and their topics. 42 studies investigated the perspective that older persons have on dying in advance—among them six regarding auto-euthanasia and assisted suicide. The other 51 studies explored the direct

Table 6.1 Investigated studies by country and topic

	Perspectives in advance on…			
	End-of-life care	Auto-euthanasia	Experiences of palliative care	Total
USA	16	–	21	37
Canada	3	–	4	7
Australia	2	–	4	6
New Zealand	1	–	–	1
Norway	4	–	4	8
Sweden	–	–	6	6
Finland	–	–	1	1
UK	5	–	7	12
Ireland	1	–	–	1
The Netherlands	–	5	1	6
Belgium	–	1	–	1
Portugal	0	–	1	1
Spain	0	–	–	0
Portugal and Spain	–	–	1	1
Israel	2	–	–	2
China	0	–	1	1
Taiwan	1	–	–	1
Japan	1	–	–	1
Total	36	6	51	93

end-of-life experiences of older persons in various settings. 22 of these studies recruited their participants among home-dwelling older persons who received care from a medical care program (3), an outpatient clinic (6), a hospital (2), or palliative home care (10); the other studies were conducted in long-term care facilities (11), in a hospice (8), in a specialized palliative care unit (1), in a palliative day care centre (1), or in more than one setting (8). The majority of the studies were conducted in North America, followed by Europe and Asia. Table 6.2 shows the studies sorted by authors, details their settings, research questions, participants, and methods. The findings were analysed and synthesized by using the same method as described in Chap. 2.

6.2 The Process of Dying and Body-Related Orientations of Action

The process of dying had a serious impact on the body-related orientations of action. It influenced the level of physical activity and rest, the desire for body protection, the tendency to negligence towards health, and the desire for food consumption and abstinence. Only the desire for sexuality was not mentioned by the older persons. Apparently, it lost its relevance at the end of life. Table 6.3 provides an overview over the different aspects of body-related orientations of action and their satisfaction, the factors that influence this satisfaction, and the behavioural and attitudinal reactions that residents use to deal with their situation.

Table 6.2 Studies by authors

Author(s)	Country	Setting	Research question	Interviewed participants	*n*	Data collection by	Research tradition
Andersson et al. (2008)	Sweden	Home care/ special care unit	To investigate what brings about a good life in the last phase of life among people receiving municipal care	Terminally ill persons, 78–100 years	17	Interviews	Not specified
Aoun et al. (2012)	Australia	Palliative home care with care aid or personal alarm	To describe the experiences of terminally ill “home alone” people using either care aides or personal alarm	Palliative care recipients, 55–91 years	26 8	Brief interviews In depth interview	Not specified
Baeke et al. (2011)	Belgium	Living at home	To explore the attitudes of older Jewish women towards euthanasia and assisted suicide	Older persons, 60–75 years	23	Interviews	Grounded theory
Ball et al. (2014)	USA	Assisted living	How end-of-life is perceived, experienced, and managed in assisted living	Residents >60 years Staff	51 32	Interviews and participant observation	Grounded Theory
Becker (2002)	USA	Living at home	To examine how Cambodian Americans and Filipino Americans view their homeland in old age and how those views affect the contemplation of death	Cambodian Americans, 50–81 years Filipino Americans, 59–97 years	48 78	Interviews (3 times)	Cultural phenomenology
Bélanger et al. (2016)	Canada	Hospital	How do health care providers and their patients discursively construct patient participation in palliative care decisions?	Older persons with cancer, 54–88 years	18	Participant observation	Ethnography and discourse analysis
Benzein et al. (2001)	Sweden	Palliative home care	To illuminate the meaning of the lived experience of hope in patients with cancer in palliative home care	Persons with cancer, 54–83 years	11	Interviews	Interpretive phenomenology

Blackhall et al. (1999)	USA	Living at home	To examine the attitudes of older people from different ethnic groups towards forgoing life support	European-, African-, Korean-, and Mexican-American >64 years	80	Interviews and questionnaire[a]	Mixed method
Bollig et al. (2016)	Norway	Nursing home	To study the views on advance care planning, end-of-life care, and decision-making in nursing homes	Residents, 66–92 years Relatives	25 18	Interviews	Interpretive description
Carrese et al. (2002)	USA	Living at home	To understand how older patients think about and approach future illness and the end of life	Older persons, Ø 86 years	20	Interviews	Ethnography
Cartwright and Kayser-Jones (2003)	USA	Assisted living	To identify the meanings attributed to end-of-life care	Terminally ill residents, 72–88 years Relatives Staff	4 4 21	Interviews and participant observation	Grounded theory
Chan and Kayser-Jones (2005)	USA	Nursing home	To investigate the factors influencing the care of terminally ill Chinese nursing home residents in the USA	Terminally ill residents, Ø 78 years[b]	34	Interviews and participant observation	Not specified
Chochinov et al. (2002)	Canada	Palliative care unit and home care	To determine how dying patients understand and define the term dignity	Terminally ill persons, 37–90 years	50	Interviews	Not specified
Coelho et al. (2016)	Portugal and Spain	Palliative care unit	To describe the comfort and discomfort experienced by inpatients at palliative care units	Terminally ill persons, 56–90 years	17	Interviews	Phenomenology

(continued)

Table 6.2 (continued)

Author(s)	Country	Setting	Research question	Interviewed participants	*n*	Data collection by	Research tradition
Dees et al. (2011)	The Netherlands	Nursing home Hospital Hospice Home care	To explore the constituent elements of suffering of patients who explicitly request euthanasia or physician-assisted suicide	Persons who requested euthanasia, 32–94 years	31	Interviews	Not specified
Devik et al. (2013)	Norway	Outpatient clinic	To explore the lived experience of older people living alone and suffering from incurable cancer in rural areas	Persons with cancer, 71–79 years	5	Interviews	Interpretive phenomenology
Devik et al. (2015)	Norway	Palliative home care	To illuminate the meaning of receiving home nursing care when being old and living with advanced cancer in rural areas	Persons with cancer, 71–92 years	9	Interviews	Interpretive phenomenology
Duggleby (2000)	USA	Hospice	To identify and describe the pain experience of older persons receiving hospice care	Older persons with cancer, >65 years	11	Interviews	Grounded theory
Duggleby and Wright (2004)	Canada	Palliative home care	To describe perceptions of hope-fostering strategies of older persons receiving palliative home care	Persons with cancer, 65–85 years	10	Interviews	Not specified
Duggleby et al. (2016)	Canada	Palliative home care	To describe the experience of taking part in a Living with Hope Program	Persons with cancer, Ø 67 years Family Caregivers	13 13	Interviews	Not specified
Eckemoff et al. (2018)	USA	Living at home	What are Russian immigrant older adults' awareness and views regarding end-of-life care?	Older persons, 60–70 years Relatives Staff	4 5 4	Interviews	Not specified

El-Jawahri et al. (2017)	USA	Outpatient clinic	To assess perceptions about hospice among patients with metastatic cancer	Terminally ill persons, 54–86 years Relatives	16 7	Interviews	Not specified
Engle et al. (1998)	USA	Nursing home	To study the experience of living–dying in a nursing home and their difference for black and white residents	Terminally ill residents, 54–91 years	13	Interviews and participant observation	Ethnography
Farber et al. (2003)	USA	Medical care program	To study the end-of-life care experience of patients, caregivers, and physicians	Terminally ill persons, 41–96 years	42	Interviews	Not specified
Fleming et al. (2016)	UK	Living at home	To understand very old people's preferences regarding care towards the end of life and attitudes towards dying	Older persons, 95–100 years Relatives	33 39	Interviews	Not specified
Forbes (2001)	USA	Nursing home	To describe end of life in a nursing home from the perspective of residents, relatives, and staff	Residents with declining health, no age specified Relatives Staff	13 n.s. n.s.	Interviews and participant observation	Not specified
Frank et al. (1998)	USA	Living at home	To explain why American Koreans have negative attitudes about life sustaining technology, but are positive about its use in general	Typical Korean American, 79 years	1	Interviews	Case study
Franklin et al. (2006)	Sweden	Nursing home	To explore the views on dignity at the end of life	Residents in early palliative phase >85 years	12	Interviews (4 times)	Not specified

(continued)

Table 6.2 (continued)

Author(s)	Country	Setting	Research question	Interviewed participants	*n*	Data collection by	Research tradition
Fried and Bradley (2003)	USA	Medical care program	What matters to seriously ill older persons making end-of-life treatment decisions?	Terminally ill persons, 60–84 years	23	Interviews and focus groups	Not specified
Fried et al. (1999)	USA	Living at home	To describe older persons' preferences for home or hospital as the site of terminal care	Older persons, 65–89 years	29	Interviews and questionnaire[a]	Mixed method
Friedrichsen et al. (2011)	Sweden	Hospice	To explore experiences and preferences of terminally ill cancer patients in the communication of truth telling in the communication of poor prognoses	Terminally ill persons, Ø 66 years	45	Interviews	Hermeneutic
Gjerberg et al. (2015)	Norway	Nursing home	To explore experiences with and perspectives on end-of-life care conversations and shared decision-making	Residents, 68–96 years Relatives	35 33	Interviews Focus groups	Not specified
Gott et al. (2004)	UK	Living at home	To explore the views of older people about "home" as a place of care during dying	Older persons >55 years[c]	32 45	Focus groups Interviews	Not specified
Hall et al. (2013)	UK	Nursing home	To explore and compare residents' views on dignity therapy	Residents, Ø 83 years	60 50 36	Interviews (Baseline) Interviews (1. Follow-up) Interviews (2. Follow-up)	Mixed method (RCT and qualitative study)

Hanratty et al. (2012)	UK	Medical care program/hospice/rehabilitation unit	To explore older adults' experiences as they move between places of care at the end of life	Terminally ill persons, 69–93 years	30	Interviews	Not specified
Haug et al. (2015)	Norway	Palliative home care/special care unit	To describe how older people with incurable cancer experience daily living while receiving palliative care	Older persons with cancer, 70–88 years	21	Interviews	Phenomenology
Haug et al. (2016)	Norway	Palliative home care/special care unit	To understand how older people with incurable cancer experience the existential meaning-making function in daily living	Older persons with cancer, 70–88 years	21	Interviews	Phenomenology
Hermann (2001)	USA	Palliative home care	To identify spiritual needs of dying patients	Terminally ill persons, Ø 72 years	19	Interviews	Not specified
Hilário (2016)	Portugal	Hospice	To provide insights on the role of inpatient hospices	Terminally ill persons, 45–80 years Relatives Staff	10 20 20	Interviews and participant observation	Ethnography
Hirakawa et al. (2017)	Japan	Living at home	To investigate end-of-life wishes and decision-making among older persons who require home care services	Older persons, 50–94 years	102	Interviews	Not specified
Ho et al. (2013)	China	Outpatient clinic/nursing home	To examine the concept of "living and dying with dignity" in the Chinese context	Persons with cancer, 61–92 years	16	Interviews	Not specified

(continued)

Table 6.2 (continued)

Author(s)	Country	Setting	Research question	Interviewed participants	*n*	Data collection by	Research tradition
Horne et al. (2006)	UK	Palliative home care	To describe patients', relatives', and nurses' perceptions of advanced care planning	Lung cancer patients, 52–87 years	9	Interviews	Grounded theory
Jack et al. (2016)	UK	Palliative home care	To explore patients' and family caregivers' experiences and perceptions of hospice at home care	Terminally ill persons, 61–90 years Relatives	16 25	Interviews	Not specified
Jarrett et al. (1999)	UK	Palliative home care	To explore terminally ill patients' and their lay-carers' experiences of community-based services	Terminally ill persons, Ø 66 years Lay carers	9 12	Interviews	Not specified
Kayser-Jones (2002)	USA	Nursing home	To investigate the process of providing end-of-life care to residents who were dying in nursing homes	Terminally ill residents, Ø 79 years Relatives Staff	35 52 66	Interviews and participant observation	Ethnography
Kayser-Jones et al. (2003)	USA	Nursing home	What are the social, cultural, clinical, and environmental factors that influence the care of dying residents?	Terminally ill residents, Ø 79 years Relatives Staff	35 52 66	Interviews and participant observation	Ethnography
Kelner (1995)	Canada	Long-term care and hospital	To explore attitudes towards end-of-life care	Chronically ill older persons, >65 years	38	Interviews	Not specified
Ko et al. (2015)	USA	Transitional housing	To explore perspectives towards a good or bad death among homeless older adults	Homeless persons Ø 65 years	18	Interviews	Grounded theory

Laakkonen et al. (2004)	Finland	Hospital	To identify the experience of older dying patients and their attitudes towards dying	Terminally ill older persons, 64–89 years	11	Interviews	Not specified
Lambert et al. (2005)	Canada	Nursing home	To describe the factors contributing to advance directives in long-term care facilities	Residents, 72–100 years	9	Interviews	Grounded theory
Lee et al. (2016)	Taiwan	Nursing home	To explore the attitudes of older nursing home residents in Taiwan towards signing their own DNR directives	Residents, 65–92 years	11	Interviews	Not specified
Leichtentritt and Rettig (1999)	Israel	Living at home	To determine meanings and attitudes towards end-of-life preferences	Healthy older persons, >70 years Sick older persons, 70–90 years	21 15	Interviews	Phenomenology
Leichtentritt and Rettig (2000)	Israel	Living at home	To determine general and essential essences of the good death phenomenon	Older persons, 60–86 years	26	Interviews	Phenomenology
Lewis et al. (2019)	Australia	Living at home	To identify factors deemed important to quality EOL care	Members of an EOL advisory group, >60 years	18 6	Focus groups Interviews	Not specified
Malcomson and Bisbee (2009)	USA	Living at home and assisted living	To explore the perspectives of healthy elders on advance care planning.	Older persons, 60–94 years	20	Interviews	Not specified
Malpas et al. (2014)	New Zealand	Living at home	To explore the reasons why some older, healthy individuals oppose physician-assisted dying at the end of life	Older persons, 66–85 years	10	Interviews	Not specified

(continued)

Table 6.2 (continued)

Author(s)	Country	Setting	Research question	Interviewed participants	*n*	Data collection by	Research tradition
MacArtney et al. (2015)	Australia	Hospice	To explore the embodied and relational experiences of the transition to inpatient care	Terminally ill persons, Ø 68 years	40	Interviews	Not specified
MacArtney et al. (2016)	Australia	Hospice	How experiences with dying within an institutional setting affect their understandings of where they might want to die	Terminally ill persons, Ø 68 years	40	Interviews	Not specified
MacArtney et al. (2017)	Australia	Outpatient clinic	How patients' experiences and understandings of their illness are shaped by interactions with a specialist palliative care outpatient clinic	Terminally ill persons, Ø 70 years	30	Interviews	Not specified
Mulqueen and Coffey (2017)	Ireland	Nursing home	To explore the preferences of residents with dementia for their end-of-life care	Residents with mild dementia, age n.s.	12	Focus groups	Nominal group technique
Munn et al. (2008)	USA	Nursing home	To examine the end-of-life experience in long-term care facilities	Residents, age n.s. Relatives Staff	11 19 35	Focus groups	Not specified
Nebel Pederson and Emmers-Sommer (2012)	USA	Palliative home care	In what ways is hospice constructed as a holistic approach to care?	Terminally ill persons, 60–90 years	10	Interviews	Social constructivism
Nelson-Becker (2006)	USA	Hospice	What helps hospice clients achieve resilience and meet psychosocial and spiritual needs	Terminally ill persons, 63–96 years	30	Interviews	Grounded theory
Ott (2008)	USA	Nursing home	To explore attitudes, opinions, and experiences with living will documents	African American residents >65 years	28	Focus groups	Not specified

Phillips and Woodward (1999)	UK	Living at home	To explore how a healthy sample of the older population feel about resuscitation	Older persons >50 years	17	Focus groups	Not specified
Richardson (2002)	UK	Palliative home care	To identify palliative patients' perception of factors that enhance feelings of health and well-being	Persons with cancer, 35–80 years	12	Interviews	Phenomenology
Romo et al. (2017)	USA	Outpatient clinic/ Medical care programs	To explore how older adults in the community with a limited life expectancy make healthcare decisions	Older persons with life expectancy <1 year, 67–98 years	20	Interviews	Grounded theory
Rosenfeld et al. (2000)	USA	Living at home and retirement community	To identify the desired features of end-of-life medical decision-making	Older persons, 72–92 years	21	Interviews	Phenomenology
Rurup et al. (2011)	The Netherlands	Living at home	To understand why some older people develop a wish to die	Older persons, 49–99 years	31	Interviews	Not specified
Ryan (2005)	USA	Medical care program	To understand the experience of older adults with advanced cancer	Persons with cancer, 65–83 years	5	Interviews	Phenomenology
Seymour (2003)	UK	Living at home	To examine older peoples' beliefs and risk perceptions regarding the use of technologies in end-of-life care	Older persons >55 years	32 45	Focus groups Interviews	Not specified
Thoresen and Lillemoen (2016)	Norway	Nursing home	To explore how family involvement helps identifying needs and promotes decision-making of residents in advance care planning discussions	Residents, 80–100 years Relatives Staff	8 10 n.s.	Participant observation and interviews	Not specified

(continued)

Table 6.2 (continued)

Author(s)	Country	Setting	Research question	Interviewed participants	*n*	Data collection by	Research tradition
Thoresen et al. (2016)	Norway	Nursing home	To explore how residents, relatives, and staff take part in end-of-life conversations	Residents, 80–100 years Relatives Staff	8 10 n.s.	Participant observation and interviews	Not specified
Tishelman et al. (2016)	Sweden	Hospice Palliative care unit Palliative home care Nursing home	To understand which aspects of surroundings are meaningful for people in the last phases of life	Terminally ill persons, 54–95 years	23	Participant produced photographs and interviews	Ethnography
Todd et al. (2016)	UK	Palliative day care centre	To explore the lived experience of medication use in life-limiting illness	Terminally ill persons, >51 years Relatives Staff	12 12 12	Interviews	Phenomenology
Towsley and Hirschman (2018)	USA	Nursing home	To describe how residents express preferences for end-of-life	Residents, 64–100 years	24	Interviews	Not specified
Towsley et al. (2015)	USA	Nursing home	To describe the communication, content, and process related to end-of-life conversations	Residents, 64–100 years Relatives Staff	16 12 10	Interviews	Not specified
van Leuven (2011)	USA	Living at home Assisted living Nursing home	Attitudes of older adults with self-reported good or poor health towards advanced care planning	Older persons at home, 78–90 years Residents (assisted living), 78–83 years Residents (nursing home), 90–92 years	11 5 2	Interviews	Not specified (secondary data analysis)

van Wijngaarden et al. (2015)	The Netherlands	Living at home	To understand the phenomenon that "life is completed and no longer worth living" as experienced by older people not suffering from a life-threatening disease	Moderately healthy older persons, 65–99 years	25	Interviews	Phenomenology
van Wijngaarden et al. (2016a)	The Netherlands	Living at home	To provide insight into what it means to live with the intention to end life at a self-chosen moment	Moderately healthy older persons, 65–99 years[d]	25	Interviews	Phenomenology
van Wijngaarden et al. (2016b)	The Netherlands	Living at home	To investigate the lived experience of a couple who chose to die together at a self-directed moment, despite not suffering from a life-threatening disease or severe depression	1 couple of older persons, 70–79 years[e]	2	Interviews	Phenomenology
Venkatasalu et al. (2014)	UK	Living at home	To explore beliefs, attitudes, and expectations expressed by older South Asians living in East London about dying at home	Older persons, 52–78 years	55	Focus groups Interviews	Not specified
Vig and Pearlman (2003)	USA	Outpatient clinic	To explore what contributes to quality of life while living with a terminal illness	Terminally ill persons, 52–86 years	26	Interviews and questionnaire[a]	Grounded theory
Vig and Pearlman (2004)	USA	Outpatient clinic	How terminally ill men describe good and bad deaths	Terminally ill persons, 52–86 years	26	Interviews and questionnaire[a]	Grounded theory

(continued)

Table 6.2 (continued)

Author(s)	Country	Setting	Research question	Interviewed participants	*n*	Data collection by	Research tradition
Vig et al. (2002)	USA	Living at home	To explore end-of-life preferences among moderately healthy geriatric outpatients with medical illness	Moderately healthy older persons, 60–74 years	16	Interviews	Not specified
Waldrop and Meeker (2012)	USA	Hospice	To explore decision-making about hospice enrolment and factors that influence the timing of that decision	Terminally ill persons, Ø 80,1 years Relatives	36 55	Interviews	Not specified
Waldrop and Meeker (2014)	USA	Hospice	To explore decisions that faced newly enrolled hospice patients and their caregivers after hospice enrolment	Terminally ill persons, Ø 83 years Relatives	35 45	Interviews	Not specified
Warmenhoven et al. (2016)	The Netherlands	Outpatient clinic	To explore the views of palliative care patients on resources and ways of coping	Terminally ill persons, 51–89 years	15	Interviews	Not specified
Whitaker (2010)	Sweden	Nursing home	What role does the body play as an existential condition during the end-of-life phase?	Residents, 79–101 years	30	Participant observation and informal interviews	Ethnography
Wilson (2000)	Canada	Living at home	What preferences do knowledgeable senior citizens have about end-of-life care?'.	Older persons who had provided end-of-life care for others, 60–85 years	49	Interviews	Grounded theory

Winland-Brown (1998)	USA	Living at home	Reasons why older persons did not make any advance directives	Older persons, 66–95 years	17	Interviews	Phenomenology
Yap et al. (2018)	Australia	Living at home	To identify factors that influence the engagement of Chinese Australians with advance care planning	Older persons >55 years	30	Interviews	Grounded theory
Young et al. (2003)	USA	Living at home	How do older persons understand terminal illness and decision-making capacity and what is their sense of agency when facing decisions about end-of-life care	Older persons, 59–83 years	18	Interviews	Grounded theory

n.s. not specified

[a] Data not included here

[b] Subsample of Kayser-Jones

[c] Same participants as Seymour (2003)

[d] Same participants as van Wijngaarden et al. (2015)

[e] Subsample of van Wijngaarden et al. (2015)

Table 6.3 Body-related orientations of action, influencing factors, behavioural and attitudinal reactions

Orientations of action and their satisfaction	
Physical activity	Declined desire for physical activity
	Longing for physical activity despite restricted ability
Satisfaction of physical activity	Further loss of mobility
Physical rest	Desire to rest and to sleep
Satisfaction of physical rest	Recovering
	Exhaustion and fatigue
	Shortness of breath
	Sleep disturbances at night
Body protection and regeneration	Desire for pain relief
	Wish for a painless death
	Treatment if a reasonable chance for improvement
	Rejection of excessive treatment
	Fear of pain during suicide
Satisfaction of body protection and regeneration	Moments of physical comfort
	Pain relief
	Lack of hygiene
	Complications
	Persistent pain
	Discomfort or harm from treatment
Negligence towards health	Ignoring health advices
	Giving up efforts to continue treatment
	No desire for pain alleviation
Satisfaction of negligence towards health	Less restricted by the treatment
Food consumption	Desire to eat
Satisfaction of food consumption	Pleasure of having a meal
	Losing the taste of food
	Aversion to Western food
	Difficulty in swallowing
	Malnutrition
Food abstinence	Loss of appetite
Satisfaction of food abstinence	Nausea
	Decreased nausea
Influencing factors	
Personal background	Illness and functional decline
	Witnessing the treatment of others
Body-related care	Treatment and medication for the management of symptoms
	Personal care
	Massage
	Lack of personal care
	Poor management of symptoms

Table 6.3 (continued)

Environmental factors	*In long-term care facilities*
	Limited availability of a physician
	Inadequate staffing
	Lack of competence in palliative care
	Lack of supervision
	Cooperation with hospice nurses
	Hiring a private caregiver in addition
	Family interferes directly with care
	Disregarding family and feeling disturbed by their presence
	For home-dwelling persons
	Bureaucratic impediments
	Lack of coordination between nurses
	Lack of communication between service providers
	Transportation problems
Behavioural and attitudinal reactions	Taking medication
	Alternative treatments

6.2.1 Physical Activity Versus Physical Rest

6.2.1.1 Physical Activity

Since suffering from a lack of energy and functional decline was common in the final stage of life, older persons had only a *declined desire for physical activity* (Ryan 2005; Whitaker 2010; Dees et al. 2011; Waldrop and Meeker 2012; Haug et al. 2015; van Wijngaarden et al. 2015). Even simple efforts like washing or shaving could make them feel exhausted. Others, however, were still *longing for physical activity despite their restricted abilities*. As one of them said:

> You need that other side of your body, the healthy part also wants its share, so to speak … the healthy part has to compensate for the sick parts. (Tishelman et al. 2016)

Even if they were unable to exercise they nevertheless appreciated the idea of doing so since it reminded them to the days when they were healthy. One woman who received hospice care told how she appreciated the presence of an exercise bicycle although she could not use it.

> I haven't been on one like this, but it can symbolize activity … because I think it is very important that it is here, that there is activity when you are in a setting like this, so that you don't just end up laying in your room, because that's not good. So… partly because you physically need to move and build your muscles and so on, because it's good for you. But also because it gives endorphins and you become happy from moving around. (ibid.)

6.2.1.2 Satisfaction of Physical Activity

Despite their desire for some physical activity, older persons in the process of dying were not able to satisfy it. The progressive decline in their physical strength rather led to a *further loss of mobility* (van Wijngaarden et al. 2016b, Hall et al. 2013, p. 363, Haug et al. 2015, p. 1041).

6.2.1.3 Physical Rest

In response to this process of decline, older persons mainly had a *desire to rest and to sleep* (Ryan 2005; Whitaker 2010; Dees et al. 2011; Waldrop and Meeker 2012; Haug et al. 2015; van Wijngaarden et al. 2015). “I am so tired. I think I need to rest a bit” was a common statement during the interviews (Whitaker 2010).

6.2.1.4 Satisfaction of Physical Rest

To a small extent, older people were able to satisfy this need and said that they had *recovered*. As one of them told, getting into a comfortable position was the highlight of his day (Ryan 2005). The predominant feeling, however, was one of continuous *exhaustion and fatigue* (Ryan 2005; Whitaker 2010; Dees et al. 2011; Waldrop and Meeker 2012; Haug et al. 2015; van Wijngaarden et al. 2015) and they felt unable to exert even minimal efforts.

> The way to my bed is endless and finally I get there. It takes a lot of energy, but once I’m in bed, it takes an hour just to gather my strength again. (Dees et al. 2011)

In some cases, this condition was further aggravated by *shortness of breath* (Forbes 2001; Duggleby and Wright 2004; Coelho et al. 2016) and *sleep disturbances at night* (Ryan 2005).

6.2.2 Body Protection and Regeneration Versus Laxness

6.2.2.1 Body Protection and Regeneration

Of even greater importance than the desire for rest was the *desire for pain relief* among older persons in the process of dying (Duggleby 2000: Benzein et al. 2001; Duggleby and Wright 2004; Laakkonen et al. 2004; Chan and Kayser-Jones 2005; Coelho et al. 2016, MacArtney et al. 2016). Pain could become the dominating force and prevented them from thinking about anything else

> If you feel really in pain and down in the dumps, it’s pretty hard to think about how far you’re going to go. (Duggleby and Wright 2004)

As a consequence, they took any effort to control it.

> I take a lot of painkillers morning and night and in between I have injections of fast-working morphine. Otherwise I wouldn’t manage. It’s essential to hold the pain in check. (Benzein et al. 2001)

Whereas many patients resorted to morphine, others preferred alternative medications like acupuncture or herbal medicine since they believed these methods to be more effective than Western medicine (Chan and Kayser-Jones 2005). There were also those who combined pharmacological and nonpharmacological strategies such as heat, positioning, and prayer to obtain a short-term relief from the pain (Duggleby 2000).

The desire for painlessness also extended to the moment when the older persons would actually die and they expressed their *wish for a painless death* (Chochinov et al. 2002; Vig and Pearlman 2004; Munn et al. 2008; Romo et al. 2017).

> Oh, just going to sleep one night and not waking up. It would be a very easy, fast way to go, no drugs, no side effects, so to me that would be real easy. (Vig and Pearlman 2004)

> Not suffering too much. Because towards the end, that's when people seem to suffer the worst. Just before the end. It's not emotional pain. It's…real pain….Sometimes I hurt so much, I'd like to take all my pills and get it over with so I wouldn't hurt. (Chochinov et al. 2002)

This was not only the wish of those who were already in the dying process, but also the wish of those who were asked to think about their dying in advance (Winland-Brown 1998; Leichtentritt and Rettig 1999; Wilson 2000; Vig et al. 2002; Seymour 2003; Gjerberg et al. 2015; Ko et al. 2015; Bollig et al. 2016; Fleming et al. 2016; Towsley and Hirschman 2018)

> A good death is when you lay down in bed and don't wake up because you're old and your body doesn't work anymore. (Ko et al. 2015)

This desire for painlessness even overruled the desire to extend one's life:

> Some people want to live long no matter what, but I don't want that. If I am in extreme pain... I would rather just end my days peacefully and not be in severe pain is my main concern. (Towsley and Hirschman 2018)

Avoidance of unnecessary pain also influenced older persons' attitude to treatment. Since medical interventions did not always turn out to be successful, they were only willing to accept *treatment if there was a reasonable chance for improvement*—and this attitude was expressed both by older people in the process of dying (Fried and Bradley 2003) and by those who considered it in advance (Rosenfeld et al. 2000)

> If there was a 50/50 chance of getting better, I'd say go ahead. But if there was a bigger chance that I'm going to lay in bed and not know anything, I don't want that. (Fried and Bradley 2003)

However, if there was no such chance, older persons *rejected an excessive treatment*—be it radio- or chemotherapy, surgery, or resuscitation—in advance and also during the process of dying since they believed that it only prolonged one's suffering without any benefit and that it prevented a natural death which was desirable at the end of life (Kelner 1995; Engle et al. 1998; Frank et al. 1998; Blackhall et al. 1999; Phillips and Woodward 1999; Leichtentritt and Rettig 2000; Rosenfeld et al. 2000; Wilson 2000; Carrese et al. 2002; Vig et al. 2002; Fried and Bradley 2003; Young et al. 2003; Vig and Pearlman 2004; Lambert et al. 2005; Ryan 2005; Munn et al. 2008; Ott 2008; Dees et al. 2011; Ho et al. 2013; Bélanger et al. 2016; Waldrop and Meeker 2014; Gjerberg et al. 2015; Ko et al. 2015;

MacArtney et al. 2015; Bollig et al. 2016; Fleming et al. 2016; Thoresen et al. 2016; Romo et al. 2017; Towsley and Hirschman 2018; Yap et al. 2018).

> A living will is I don't want to be hooked up to machinery to save my life … Because I don't want my life to be prolonged. When my time is up, I want to die (Carrese et al. 2002)

> I say: I have made my decision. I don't want you to treat me any longer. Someone says, now you are probably too weak for chemo. I say: if I'm not too weak and they want to give me chemo, I will refuse it, because in the little time that is left to me I want quality of life, not quantity of life. I decided that year ago: if this were to overcome me, then that's what I would choose (Dees et al. 2011)

Unbearable pain at the end-of-life was also one reason why some older persons requested assisted suicide (Dees et al. 2011). One thing, however, that deterred those who considered a self-chosen death was *fear of pain during suicide*:

> I definitely do want to go to the other side where all my loved ones are, though I'm scared to death of the crossing. It mustn't be too painful, oh dear, oh dear! (…) So, it's just that fear. I'm so afraid to die of suffocation. But still, it's contradictory. Because if you truly wanted to die, you would say: Well, it might be very nasty for a bit, but then it's over'. But I so deeply want to die in a gentle way. (van Wijngaarden et al. 2016a)

6.2.2.2 Satisfaction of Body Protection and Regeneration

To some extent, the desire for physical integrity and painlessness could be satisfied when older persons received palliative care. There were *moments of physical comfort* when they were massaged or positioned in an appropriate way (Laakkonen et al. 2004; Ryan 2005; Aoun et al. 2012)

> Those hands wander skilfully and massage me with oil…I enjoy it very much, even though I have pain. When the hands know what they are doing, I don't have so much pain. (Laakkonen et al. 2004)

Those who stayed in a hospice or had a palliative home care service also told about *pain relief* due to adequate care (Engle et al. 1998; Richardson 2002; Farber et al. 2003; Hilário 2016).

Others, however, experienced discomfort or physical harm when they received care or treatment. Some just felt disturbed by *a lack of hygiene* in the palliative care setting and complained about dirty laundry bags that nobody took concern to remove (Tishelman et al. 2016). Others suffered from serious *complications* like falls or pressure ulcer that contributed to the worsening of their condition (Kayser-Jones 2002; Kayser-Jones et al. 2003; Aoun et al. 2012). Kayser-Jones et al. (2003) who observed the process of dying in regular nursing homes reported that 54% of the residents suffered from pressure ulcer and 82% of them died with pressure ulcers—figures that apparently indicate a severe lack of care in the investigated facility. More often, however, dying persons told about their *persistent pain* that was sometimes accompanied by further symptoms like nausea or shortness of breath and about failed attempts of alleviation (Engle et al. 1998; Duggleby 2000; Forbes 2001; Chochinov et al. 2002; Vig and

Pearlman 2003; Duggleby and Wright 2004; Whitaker 2010; Waldrop and Meeker 2012; Devik et al. 2013; Ho et al. 2013)

> Oh yes when I had that terrible pain and it got so bad. I phoned Dr. B. and I said I can't stand it anymore. I just can't. I lie at night and I have for months and they don't help, those pills that he gave me didn't help. I said what… what shall I do? Well he says I can't do anything about it. (Chochinov et al. 2002)

Some older persons also had to endure *discomfort and harm from treatment*. They had difficulties in swallowing prescribed medication (Todd et al. 2016), suffered from side-effects of chemotherapy (Nebel Pederson and Emmers-Sommer 2012; Bélanger et al. 2016; Haug et al. 2015; Todd et al. 2016), or got injured during intubation (Fried and Bradley 2003):

> If [the tube] doesn't go in right, they cut you up. You bleed, you're hurting, so on and so forth. Once it is in you can't talk. Your mouth is dry and it hurts, even when they take it out. (Fried and Bradley 2003)

6.2.2.3 Negligence Towards Health

Given these complaints, it was not surprising that dying persons had a declined interest in getting treatment. Some of them, however, even disliked to observe treatment although it was beneficial. They *ignored health advices* since these resulted in a loss of their overall quality of life:

> First of all, I can't get my shoes on in the morning, and I can't breathe. So I try to stay away from salt. And I can do pretty good, but just every once in a while I'll just say, the hell with it, and just sprinkle some on there and eat anyway. And you know there's a price to be paid for doing that, but you do it (Vig and Pearlman 2003)

Others *gave up their efforts to continue treatment*. They stopped taking their medication due to difficulties in swallowing them (Duggleby 2000) or they lost interest in monitoring their blood pressure since they thought it was pointless because they were about to die anyway (Todd et al. 2016). Ho et al. (2013) also reported about Chinese older persons who had *no desire for pain alleviation*, partly because pain medications made them feel numb and partly because they considered bearing pain as a virtue:

> It is okay to live with pain because it remains me that I am alive…Like the old Chinese saying, 'If you wish to be the best man, you must be prepared to suffer the bitterest of the bitter.' Sometimes the medicine makes me so numb that I cannot feel anything… like I am not even here. (Ho et al. 2013)

6.2.2.4 Satisfaction of Negligence Towards Health

As suggested by the quotation above (Vig and Pearlman 2003), older persons who were not so much concerned about their health in the process of dying *felt less restricted by their treatment*. They could avoid some side-effects of the prescribed medication, and, despite unpleasant symptoms, had at least some pleasures in the remaining days of their lives.

6.2.3 Food Consumption Versus Food Abstinence

6.2.3.1 Food Consumption

Despite their declining condition older person in the process of dying still had a *desire to eat* and they sometimes even had a good appetite (Kayser-Jones 2002; Kayser-Jones et al. 2003; Vig and Pearlman 2003; Aoun et al. 2012; Tishelman et al. 2016). As we saw in the previous quotation (Vig and Pearlman 2003), the desire to enjoy a meal could even outweigh the tendency to avoid unpleasant symptoms that might result from the consumption of food.

6.2.3.2 Satisfaction of Food Consumption

Some older persons told about their *pleasure of having a meal* (Aoun et al. 2012; Ho et al. 2013; Tishelman et al. 2016). They were satisfied with the mere fact that they could still eat normally and their pleasure could even be increased if someone else prepared the meal for them.

> [Care aide] always does the dishes and makes me lunch…if someone cooks for you, you always eat more you know. (Aoun et al. 2012)

Others, however, could not satisfy their desire for food consumption. This had several reasons. Some older persons suffered from a sensory disorder and *lost the taste of food*:

> When I'm going to make preparations for dinner, I often make a cheese course with Camembert, Brie and a piece of blue cheese. Look, of course I still know how it tastes (…) and I feel the substance in my mouth and then I try to imagine what the taste is like, but there is nothing. So, well, it's not inspiring. Basically, it's not fun. (van Wijngaarden et al. 2016b)

Chinese older persons, who were dying in American nursing homes, expressed an *aversion to Western food* which prevented them from eating:

> See what they give me for dinner? A sandwich. They give me a scoop of rice with dinner. What am I supposed to eat the rice with? Rice is supposed to come with some kind of main dish like meat or vegetables. You can't just eat white rice! The ironic thing is that the doctor came to see me. He encouraged me to eat more food. How can I eat more if this is what they're serving me? (Chan and Kayser-Jones 2005)

Others could not satisfy their desire to eat since they had *difficulty in swallowing* (Dees et al. 2011), and if dying older persons were unable to feed themselves and did not get the required help they suffered from thirst and finally *malnutrition*. Kayser-Jones et al. (2003) recalled such a dying person who complained about thirst and hunger when they visited her in a nursing home:

> Mrs. Carson was reaching for a carton of milk on her bedside table. She was weak and her hand was shaking. She had lost 19 pounds in 1 month. She was too weak to suck on the straw, but using the straw as a pipette, the Research Assistant was able to give her 120 ml of milk. She died the following day. (Kayser-Jones et al. 2003)

6.2.3.3 Food Abstinence

On the other hand, side-effects of treatment, especially chemotherapy, could result in a *loss of appetite* and the dying persons did not want to eat any longer (Engle et al. 1998; Ryan 2005; Devik et al. 2013; Ho et al. 2013).

> You see, I have something on my tongue, they (at the hospital) said it was fungus, and I don't have any appetite. The food doesn't taste anything. It's a different taste (Devik et al. 2013)

> I ain't ate a thing, and I ain't even hungry. And I get up the next mornin', won't be hungry. (Engle et al. 1998)

6.2.3.4 Satisfaction of Food Abstinence

Despite their abstinence from food, older persons who still received chemotherapy experienced *nausea* which further decreased their desire to eat (Duggleby and Wright 2004; Ryan 2005; Dees et al. 2011; Devik et al. 2013):

> I was simply nauseous and my energy was just running out. And I said that I wished that, just for a short period of time, I could eat normally and not have to fight to keep it down and that I wanted to have a little more energy. (Dees et al. 2011)

Only if such treatment was stopped or its side-effects were adequately controlled, did the older persons tell about a relief of symptoms and *decreased nausea* (Richardson 2002).

6.2.4 Influencing Factors

The satisfaction of body-related orientations of action was influenced by personal background, body-related care, and environmental factors which also determined how caregivers and other medical staff could provide body-related care.

6.2.4.1 Personal Background

First and foremost, body-related orientations of action depended on the physical condition of the older persons. *Illness and functional limitations* accompanied the process of dying, restricted both physical activity and consumption of food, and triggered a desire for physical integrity and pain relief (Benzein et al. 2001; Farber et al. 2003; Andersson et al. 2008; Whitaker 2010; Ho et al. 2013). The rejection of excessive treatment among those in the process of dying resulted from harm and prolonged suffering caused by such treatment (Engle et al. 1998; Fried and Bradley 2003; Vig and Pearlman 2004; Lambert et al. 2005; Ryan 2005; Munn et al. 2008; Ho et al. 2013; Waldrop and Meeker 2014; MacArtney et al. 2015; Romo et al. 2017). The experience of *witnessing the treatment of others* played also an important role in their rejection of life-prolonging treatment (Romo et al. 2017).

> I wouldn't [want to be put on a breathing machine]. I've seen one lady that was on support. Her granddaughter had her put on life support, but I would not want to do that. It's sort of terrible to me. (Romo et al. 2017)

6.2.4.2 Body-Related Care

Given the dominant experience of pain, *treatment and medication for the management of symptoms* was of utmost importance for the dying persons (Cartwright and Kayser-Jones 2003; Ball et al. 2014; Bélanger et al. 2016; Devik et al. 2015; Jack et al. 2016). To promote physical well-being, *personal care* was indispensable (Cartwright and Kayser-Jones 2003; Devik et al. 2015). This included washing and grooming, assistance with eating and drinking, as well as with mobilization within the scope of the remaining physical abilities. Some older persons also appreciated getting a *massage* (Laakkonen et al. 2004).

In contrast to this, pain and physical discomfort occurred when there was a *lack of personal care* (Kayser-Jones 2002; Kayser-Jones et al. 2003) and *poor management of symptoms* (Forbes 2001; Kayser-Jones 2002; Kayser-Jones et al. 2003) as it was observed in some nursing homes. Kayser-Jones et al. (2003) describe in one of their field notes the condition of such a dying resident who had to endure inadequate care:

> This resident had a very distinct odour that got worse over the course of his five days in the nursing home. It was the odour of an unwashed body. He received poor mouth care. His lips and mouth were extremely dry, and a thick, pasty mucus had built up on his lips. (Kayser-Jones et al. 2003)

6.2.4.3 Environmental Factors

The body-related care of the dying persons depended of course on the organizational framework. As for nursing home residents, inadequate pain management was partly due to the *limited availability of a physician* who visited in some places only once every 30–60 days (Kayser-Jones 2002). Far more serious, however, was the impact of *inadequate staffing* (Kayser-Jones 2002; Cartwright and Kayser-Jones 2003; Kayser-Jones et al. 2003; Laakkonen et al. 2004; Munn et al. 2008). As one resident observed:

> I think they are really short around here now. I see the same girls here from morning until night. They are working overtime every day, I'm sure. (Cartwright and Kayser-Jones 2003)

According to caregivers and nurses the shortage of staff was due to inadequate payment:

> Nobody can live on $6 to $7 an hour. We are the heroes; heroes without a salary, the ones that do the work. It would be good if we had only 6 patients. If you have 6 patients, it's great. You have time to talk with them, to feed them well, and you can check them often. (Kayser-Jones et al. 2003)

Furthermore, regular staff in nursing homes *lacked competence in palliative care* (Forbes 2001). Some of them readily admitted that they never had received training related to death and dying. Another aggravating factor was that in the investigated nursing homes, care was actually provided by nursing assistants who were less educated and *lacked supervision* from registered nurses (Kayser-Jones et al. 2003). The skill-mix in these facilities was based on a *hierarchy* where the medical director was in command of the entire staff and the charge nurse was in command of the aides who out of anger or feelings of not being responsible withheld information that would have helped to alleviate the condition of the dying person (Forbes 2001). Some long-term care facilities *cooperated with hospice nurses* to improve this situation. This cooperation, however, turned out to be insufficient since hospice nurses complained about the lack of knowledge of nursing aides and their unwillingness to provide information about the dying person. Consequently they were reluctant to delegate tasks to them. In reaction to this attitude, nursing aides, who were in charge of the actual care, felt excluded from the care process. To prevent poor care, some families *hired a private caregiver* in addition to stay with the dying person at night (Cartwright and Kayser-Jones 2003). More often, however, the *family interfered directly with the care* (Kayser-Jones 2002; Cartwright and Kayser-Jones 2003; Kayser-Jones et al. 2003; Chan and Kayser-Jones 2005). They came regularly to check on the dying persons, brought food that they liked, tried to feed them, talked on their behalf with the staff, and sometimes they even stayed overnight in the facility. Such interference was, however, not always welcome. Staff tended to *disregard the family* and sometimes *felt disturbed by their presence* and reacted accordingly (Kayser-Jones 2002; Munn et al. 2008).

Also home-dwelling older persons had to endure restrictions. *Bureaucratic impediments* could delay the provision of assistive devices that facilitated the satisfaction of physical needs (Jarrett et al. 1999; Hanratty et al. 2012). For reasons that were not comprehensible to the older persons, services were restricted to certain time limits or they were told that another authority was responsible for a particular application. One older man with swollen feet, for example, did not find the appropriate help with footwear and was housebound for several weeks (Hanratty et al. 2012). A *lack of coordination between nurses* could result in an unforeseen lack of necessary medication:

> She'd say 'oh [district nurse] hasn't left me enough of this one, there's only two of this one. Panic woo-ah so we'd have to get to doctors, go to chemist, bring it back. (Jarrett et al. 1999)

This situation was sometimes further complicated by a *lack of communication between different service providers* involved in the treatment of the dying person (Jarrett et al. 1999; Hanratty et al. 2012)

> They don't know what they're doing half the time up there. I was on that frusemide right? Been on it since the day I came out of hospital. One day he said to me I think we'll try you on frusemide, heh, been on that since I come out of hospital. (Jarrett et al. 1999)

Communication failures occurred in particular during referral from hospital to home:

> They told me in the hospital before I left that the district nurses would be in touch, and the occupational therapist. Now I was home for a week, now I had to phone up the district nurses and ask them when they were coming out to treat my legs. They said we didn't know you were out of hospital. We haven't had a referral. (Hanratty et al. 2012)

Since home-dwelling patients had to come to the outpatient department for examinations and treatment, they also had *transportation problems*.

> I have to go to (X) hospital for several injections a couple of times per week and if for instance I went by taxi it cost me 100 dollars or more return but if I take public transport I have to take three different busses and a train and if everything went bad it could take me up to 6 hours in transport. (Lewis et al. 2019)

6.2.5 Behavioural and Attitudinal Reactions

To cope with their situation and to alleviate their pain the dying persons resorted to *taking their medication* (Duggleby 2000: Benzein et al. 2001; Duggleby and Wright 2004; Laakkonen et al. 2004; Chan and Kayser-Jones 2005; Coelho et al. 2016, MacArtney et al. 2016). The only exception were those who experienced unpleasant side-effects from their medicaments, had difficulty in swallowing them (Nebel Pederson and Emmers-Sommer 2012; Bélanger et al. 2016; Haug et al. 2015; Todd et al. 2016), or were inclined to a rather stoic attitude of pain endurance (Ho et al. 2013). Some dying persons supplemented biomedical methods with *alternative treatments* like traditional Chinese medicine, prayer, or meditation (Duggleby 2000; Chan and Kayser-Jones 2005). If treatment, however, became painful and futile, its rejection was the attitudinal reaction that aimed to protect physical integrity in the process of dying.

6.3 The Process of Dying and Social Orientations of Action

The satisfaction of body-related orientations of action influenced the social orientations of action of older persons in the process of dying. Pain, loss of energy, and declined mobility made it necessary to find a new balance between the opposing needs for self-reliance versus being cared for, influencing others versus paying attention to their needs, adjustment to social norms versus unconventionality, and closeness versus distance. But also the confrontation with the necessity of advance care planning required a readjustment of these orientations of action. Table 6.4 provides an overview over the social orientations of action, the various degrees of their satisfaction, the factors that influence this satisfaction, and the behavioural and attitudinal reactions of the residents.

6.3.1 Self-Reliance Versus Being Cared for

6.3.1.1 Self-Reliance

Despite their poor health and their declining physical abilities many older persons still had a desire for self-reliance (Hermann 2001; Nelson-Becker 2006; Andersson et al. 2008; Devik et al. 2013; Ho et al. 2013; Haug et al. 2015;; Warmenhoven et al. 2016). They had been used to take care of themselves throughout their life and were not inclined to abandon this habit:

Table 6.4 Social orientations of action, influencing factors, behavioural and attitudinal reactions

Orientations of action and their satisfaction	
Self-reliance	Desire for self-reliance
	Fear of becoming care-dependent
	Reluctance to ask for help
Satisfaction of self-reliance	Maintained self-reliance
	No need for psychological support
	Lost self-reliance
	Becoming dependent on the help of others
Being cared for	Desire for family care
	Desire for professional care
	Desire for empathy and a relationship of trust
	Desire for support in deciding on end-of-life care
	Desire to find help to commit suicide
Satisfaction of being cared for	Feeling of being cared for
	Comfort and relief through practical support
	Feeling of being safe
	Feeling reassured
	Medical care with commitment
	Neglect of care needs
	Lack of support and attention
	Inadequate help
	Having to manage care by themselves
	Fear of becoming helpless and abandoned
	No help to commit suicide
	No support for decisions about end-of-life care
Exerting influence on others	Desire for control over one's own life
	Desire to maintain control over one's own care
	Desire to participate in end-of-life decisions
	Desire to be informed about prognosis and treatment
	Making end-of-life decisions on their own
	Desire to refuse futile treatment
	Desire for a self-determined death
	Fear that life support is stopped against own will
	Joint decision with the family
	Leaving decisions to God
	Expecting family to make decision
	Desired paternalism
	Simply accepting the decision of others
Satisfaction of exerting influence on others	Being in control over care
	Lack of control over treatment
	Restrictions due to imposed rules and routines
	Empowered to decide about end-of-life care
	Confident that decisions will be respected
	Lack of information and participation
	No influence on end-of-life decisions
	Deprived at the right to commit suicide

(continued)

Table 6.4 (continued)

Attention to the needs of others	Fear to become a burden for family and friends
	Fear that prolongation of life could place undue burden on relatives
	Fear to burden others with suicide
	Not wanting to burden families with decisions about end-of-life care
	Fear of burdening caregivers
	Withholding complaints
Satisfaction of attention to the needs of others	Being a burden
Social adjustment	Observing good manners
	Dying in accordance with social norms
	Complying with family's desire to continue
	Observing the taboo of suicide
Satisfaction of social adjustment	Feeling ashamed
	Moral satisfaction
Unconventionality	Rejecting moral taboos
	Desire for more tolerance
Satisfaction of unconventionality	Restricted by social rules regarding death and dying
Closeness	Desire for social participation
	Maintaining contacts to old friends
	Searching for new contacts to like-minded persons
	Trying to establish contacts to roommates
	(Desire for) close relationship to staff
	(Desire for) close contact to the family
	Wish to be surrounded by familiar persons in the moment of dying
Satisfaction of closeness	Having contacts to old friends
	Loss of old contacts
	Encouragement from like-minded persons
	Finding no one to talk to
	Kindness and attentiveness of staff
	Close connection to some caregivers
	Contact to caregivers as a substitute
	Good relationship to physician
	Distanced relationship to staff
	Having a close relationship to family
	Limited contact to family
	Missing the contact to the spouse
	Loneliness
Distance	Desire for withdrawal
Satisfaction of distance	Enjoying privacy
	Restrictions of privacy

Table 6.4 (continued)

Influencing factors	
Personal background	Lack of financial resources
	Cognitive impairment
	Socio-economic status
	Access to information
Care for social needs	Domestic support
	Taking time and giving attention
	Comforting personality
	Competent personality
	Restricted to task performance
	Inattentiveness of the physician
	Lack of coordination
	Useless bureaucracy
	Inattentiveness to both physical and emotional needs
	Withdrawal from the dying
	No information about treatment options and advance care planning
Environmental factors	*Regarding care*
	Suitability of the home
	Availability of family care
	No family (available)
	Access to the internet
	Visits from family or friends
	Presence of the family at the moment of dying
	Regarding end-of-life decisions
	Relatives are used to take over decisions
	Decisions according to culture and tradition
	Believe to know the expectations of the dying person
	Discussing end-of-life care in the family
	Avoidance of end-of-life discussions in the family
	Family members want to be involved in decisions
	Family members not involved in decision-making process
Behavioural and attitudinal reactions	Seeking care and treatment
	Controlling caregivers
	Avoiding care facilities
	Inviting family and friends
	Establishing a positive relationship with caregivers
	Setting up a living will or a do-not-resuscitate order
	Leaving decisions to others
	Searching for assistance to commit suicide

> I just need to do for myself. I always have and I guess I always want to. (Hermann 2001)

> So when I say that I like to be independent, that includes really basic things like making my bed, doing my laundry, cleaning. (Nelson-Becker 2006)

Not surprisingly, older persons who were still healthy and considered advance care planning had the same concern (Leichtentritt and Rettig 2000; van Wijngaarden et al. 2016a; Hirakawa et al. 2017; Lewis et al. 2019). Behind the desire for self-reliance was the *fear of becoming care-dependent* which was shared by those who were dying (Chochinov et al. 2002; Fried and Bradley 2003; Vig and Pearlman 2004; Dees et al. 2011; El-Jawahri et al. 2017) and those who considered this process in advance (Blackhall et al. 1999; Leichtentritt and Rettig 2000; Carrese et al. 2002; Lambert et al. 2005; Ko et al. 2015; van Wijngaarden et al. 2016a).

> I don't want to have to sit in a chair and have everyone come to me, lift me out of bed, bring me to the bathroom, bring me my meals. (Fried and Bradley 2003)

For some, the idea of being in such a condition was intolerable and they preferred to die by ending treatment or even by assisted suicide.

> I think we should all when we get to the stage when we have to be fed and diapered and bathed, I think we should be given a needle and put to sleep. (Lambert et al. 2005)

Given this attitude, these older persons were *reluctant to ask for help* (Nelson-Becker 2006; Devik et al. 2013):

> I've always been a caregiver and I can't give anybody care now. I'm being cared for – the role is reversed. I don't like it. (Nelson-Becker 2006)

6.3.1.2 Satisfaction of Self-Reliance

To some extent, these older persons were able to *maintain their self-reliance* (Chochinov et al. 2002; Richardson 2002; Duggleby and Wright 2004; Ho et al. 2013; Haug et al. 2015; Warmenhoven et al. 2016) and were satisfied about it—even if it took more time and effort:

> Normally [this activity] takes ten minutes. Well, it takes me one hour […] But I am happy and thrilled that I can still do it, that I am still able. (Warmenhoven et al. 2016)

Some were even able to regain lost self-reliance after a period of restrictions:

> Earlier this winter, I needed help with everything because of a fracture in my back. The pain experiences in this period have been more troublesome than the cancer illness and treatment periods. Now I appreciate being self-sufficient, doing many of the things I used to do in the house and in the garden (Haug et al. 2015)

Some older people also claimed that they were self-reliant with regard to their emotional balance and that they had *no need for psychological support*:

> I don't think I have any psychological needs for them to take care of. I'm an extremely self-reliant person. I don't need a lot of help from anybody. (Nebel Pederson and Emmers-Sommer 2012)

Due to their increasing physical deterioration, however, dying older persons had to give up their activities little by little until they finally *lost their self-reliance* (Duggleby 2000; Benzein et al. 2001; Chochinov et al. 2002; Farber et al. 2003; Ryan 2005; Franklin et al. 2006; Whitaker 2010; Dees et al. 2011; Rurup et al. 2011; Nebel Pederson and Emmers-Sommer 2012; Hall et al. 2013; Ho et al. 2013; van Wijngaarden et al. 2015; Tishelman et al. 2016):

> Well, it's been terrible, like a horror movie, when you can't do nothing for yourself. I can get to the bathroom. I can get to the kitchen table and the bed. Other than that, I stay right here or in that bed […]. A person that's always been well and all of the sudden, you can't do nothing for yourself. I can't even … I can barely open a can […] I feel like I've gone from being a king to being a pauper. (Ryan 2005)

As a consequence they *became dependent on the help of others* (Dees et al. 2011; Rurup et al. 2011; Devik et al. 2013; Ho et al. 2013; Coelho et al. 2016):

> I am totally dependent on my wife to carry me down the stairs, out of my home and into the outside world. (Ho et al. 2013)

6.3.1.3 Being Cared for

In view of their growing need for assistance, however, many older people also had a desire to be cared for. Some of them had an explicit *desire for family care* (Becker 2002; Hirakawa et al. 2017; Eckemoff et al. 2018). This desire was particularly pronounced among immigrants who still had strong family ties. Some of them even wanted to return to their home country for this reason when they would be dying:

> When I am really old, like 72 or 73, I will go home to the Philippines. All people will die, and I don't want to die here. I'll tell you why I don't want to die here. In the Philippines, if I die there, my family will watch me all the time. (Becker 2002)

On the other hand, there was also a *desire for professional care* since caring for the dying was not perceived to be a "natural" skill but rather something that required a degree of training that was lacking in the family (Nebel Pederson and Emmers-Sommer 2012; Coelho et al. 2016; MacArtney et al. 2016; El-Jawahri et al. 2017; Lewis et al. 2019). During the process of dying, this desire came to the fore when symptoms became unbearable and caused the dying person to seek care in a hospital or hospice:

> The pain and the shortness of breath, that is the thing I was not able to control, and that was creating some fearful respect. At the hospital I am well, arriving home, I stay there for a little longer and that's it… (Coelho et al. 2016)

Older persons who considered end-of-life care in advance had similar opinions (Fried et al. 1999;; Seymour 2003; Gott et al. 2004):

> When you're that bad, go [to the hospital], This way you're right there. If you need them [the nurses], they're there. (Fried et al. 1999)

Some of them knew about the difficulties of symptom management from their own experience of caring for a dying relative.

> When mum was in such a bad state near the end and it was obvious she was going to die within days and I was just more or less left to see to her. Now I was panicking because I'm thinking what does she need? You know I didn't even know how to put the pillows to make her as comfortable as a nurse and the district nurse could see that and it was her who said 'I think you need intensive nursing now don't you?' (Gott et al. 2004)

The desire for professional care implied also a *desire for empathy and a relationship of trust* with caregivers, nurses, and physicians since care was not restricted to the technical aspects of treatment (Farber et al. 2003; Malcomson and Bisbee 2009; Towsley et al. 2015; Warmenhoven et al. 2016; Romo et al. 2017). The need for care could only be met if its emotional aspect was taken into account. It referred to both medical doctors and nurses:

> If the specialist checks my breathing, checks whether my abdomen hurts etc., she could also ask if I am still feeling happy. Or if I am, I don't know, crying more, or something like that. (Warmenhoven et al. 2016)

> They have to be here and have one person get their confidence, someone they can talk to, be it one of the nurses who some of them are very wonderful. (Towsley et al. 2015)

To establish such a relationship of trust older persons preferred to get care and treatment by the same physician or nurse since these were familiar with their needs (Farber et al. 2003; Haug et al. 2015). Immigrants were also inclined to search for health professionals who had the same cultural background (Yap et al. 2018).

A need for care was also evident in the *desire for support in deciding on end-of-life care*. Some older persons said that they needed someone to listen to them and to answer questions that preoccupied them:

> What I would do, and what I want help with and such. I would've liked to talk to them more about it. (Gjerberg et al. 2015)

For older people who wanted to end their lives, being cared for meant *desire to find help to commit suicide*:

> I want someone…I want someone to help me. I want someone to make it easy for me to, so to say, place my soul in the hands of the Lord. (van Wijngaarden et al. 2016a)

6.3.1.4 Satisfaction of Being Cared for

Several older persons were satisfied by the care they received. If nurses or doctors took their time, paid attention to their needs, and gave them sufficient information they had a *feeling of being cared for* (Fried and Bradley 2003; Franklin et al. 2006; Devik et al. 2013; Ho et al. 2013; Haug et al. 2015; Coelho et al. 2016)

> This team that cares us so well, with such kindness… I think that for a patient it is as important a good medication or treatment as it is a humanised and nurtured care. (Coelho et al. 2016)

> I have a great contact person here at the nursing home. She helps me with everything and she is lovely. There is also a man who is wonderful. They have a lot to take care of, you see everyone likes them. (Franklin et al. 2006)

In part, this feeling was due to *comfort and relief through practical support* that was provided by caregivers or nurses when dying persons stayed in their own home (Richardson 2002; Aoun et al. 2012; Jack et al. 2016). The support was wide ranging and included domestic work, filling in forms, financial advice, obtaining equipment, organizing prescriptions, and help with transportation:

> She's [care aide] changed my life quite a lot. She's taken away a lot of the burdens you know. There's certain things you just can't do. (Aoun et al. 2012)

> And yes, she's [care aide] taken me there [Dermatologist], and it doesn't take long and on the way back we call in and do a bit of shopping. So really and truly she's been a godsend. (ibid.)

The other aspect that contributed to the feeling of being cared for was *getting treatment for physical symptoms* that gave noticeable relief. Some of the home-dwelling dying persons described their satisfaction with the prescriptions and advices of the palliative nurses:

> They seem to know what to prescribe to help you through your problem. (Richardson 2002)

> [Nurses] knowing I needed the artificial saliva for night time use. It was very, very practical and I'd never heard of it before. (Jack et al. 2016)

Positive experiences with practical help and symptom management gave older people a *feeling of being safe* in case of a problem—be it at home, in a hospital, or in a palliative ward (Jarrett et al. 1999; Richardson 2002; Andersson et al. 2008; Aoun et al. 2012; Waldrop and Meeker 2012; MacArtney et al. 2015; Coelho et al. 2016).

> [Care aide] given me a sort of security that I've never had lately, you know what I mean? Because I was up in the air for a while, you know, not knowing what was happening yes… And, now I'm, I'm feeling good. (Aoun et al. 2012)

For home-dwelling older persons the sense of security was increased by wearing a personal alarm (ibid.). For older persons who stayed in a palliative ward the same feeling resulted from the permanent presence of the nurses:

> If you need a nurse, a nurse will come immediately. If you need anything, just call them and they will come here straightaway. It is the comfort of knowing that if I need to call the nurses, they come here immediately. (Coelho et al. 2016)

Older persons also *felt reassured* when they could talk to nurses or doctors about their fears and when health professionals responded to their fears (Richardson 2002; Ryan 2005; Horne et al. 2006; Haug et al. 2015):

> To be honest with you, I asked her [nurse] the questions, in some ways in that, I said to her like, is it painful towards the end and that sort of thing, you know. And she said not today, she said that nobody should suffer today, towards the end since cancer sufferers used to do. There are different medications and morphine and whatever. Should be able to pass away nice, quiet and peacefully (Horne et al. 2006)

Such reassurance was also found when older persons received *medical care with commitment* (Jarrett et al. 1999; Farber et al. 2003; Vig and Pearlman 2003). This meant that the physician called to inquire about the dying person's condition, visited him or her at home, and took the time to inform him or her about all aspects of care and treatment. The emotional aspect of the desire for being cared for was of course satisfied when dying persons received care from their families and friends (Vig and Pearlman 2003; Duggleby and Wright 2004; Andersson et al. 2008; Coelho et al. 2016):

> It's amazing sometimes the love that somebody will give you and it's maybe not much, like a card of some kind, or a little pin, it means so much. It just gives you a lift. Somebody really cares and I think caring and love that goes hand in hand. (Duggleby and Wright 2004)

Although these statements suggest that the desire for care was often satisfied, observations in nursing homes indicate that dying older persons may also suffer from a hunger, thirst, pain, and complications like pressure ulcer due to *neglect of care needs* (Kayser-Jones 2002; Kayser-Jones et al. 2003). Some older persons also complained about *a lack of support and attention* from caregivers and nurses (Engle et al. 1998; Franklin et al. 2006; Andersson et al. 2008; Hanratty et al. 2012; Devik et al. 2013). As they said, requests for help remained unheard, and sometimes rude behaviour even forced them to become self-reliant.

> [Nursing assistant] said, 'You get up outa that bed! Get those lazy bones up outa that bed.' But I be wantin' to sleep, and she made me get up. I been gettin' up ever since. (ibid.)

In a similar way, home-dwelling older persons had the feeling that they were not welcome when they were treated in a hospital:

> They [health care staff] wanted to get rid of me, that I understood, there were people to take my place at once. So before I left my bed was made up for a new one. (Andersson et al. 2008)

They were also incidences of *inadequate help*, such as a night-time episode of an older woman who was being cared for in a nursing home and had to be transferred to a hospital:

> I couldn't breathe—she just looked at me, wringing her hands and said, did I want her to call 911? I said 'yes'! (Cartwright and Kayser-Jones 2003)

Due to organizational shortcomings older persons sometimes felt that they *had to manage their care by themselves* (Hanratty et al. 2012; Devik et al. 2013). There was no support for access to examinations and treatment and for discharge from hospital.

> I have to order blood tests myself, it takes time when I call and only meet an answering machine. I feel that I don't have time for this. (Devik et al. 2013)

> They sent me home I had no medication to come home with, just I had just got my old insulin but they gave me no instructions, no knowledge, nothing and the sister was on the phone when I left, and she never bothered, she just waved like that when I went out. (Hanratty et al. 2012)

Due to such experiences of being neglected some older persons were overwhelmed by a *fear of becoming helpless and abandoned* that made them consider suicide:

> Well anyway, it's loneliness and fear, anxiety you might call it. Look, my mind is still sharp, but if I suffer a terrible stroke again, I'll probably lose my mind…I want to avoid that! […] certain images frequently appear in my mind: it can happen to me again. And the big question is: who will help me? Really, who will help me then? So I just want to keep ahead of that. (van Wijngaarden et al. 2016a)

At the same time, some of these older persons felt that there was no help for committing suicide and they had to rely on themselves.

> Sadly, it's impossible for me to sail away like this. I'll have to do it all by myself. (…) We were able to support my partner with making choices and with help. But I…I'll have to do it by myself, at least for a large part… (ibid.)

There were also older persons who felt that there was *no support for decisions about end-of-life care*. They found no one to listen to them and to answer the questions that preoccupied them (Malcomson and Bisbee 2009; Gjerberg et al. 2015; Romo et al. 2017). Others were expected to make end-of-life care decision upon admission to a long-term care facility but they were not given any advice or time to think about it (Thoresen et al. 2016).

6.3.2 Exerting Influence on Others Versus Attention to the Needs of Others

6.3.2.1 Exerting Influence on Others

The desire for self-reliance was rooted in a *desire for control over one's own life*. However, since people are never completely independent from others, they want to influence at least those they have to rely on. As one older woman with a motor neuron disease put it:

> Quality of life when I think about myself is about having a say in my life and being able to have some self-agency and to be able to have a say in what happens to me and to be able to have some capacity to direct things. (Lewis et al. 2019)

First of all, exerting influence referred to the *desire to maintain control over one's own care*. For this reason, some older persons who stayed in long-term care facilities forged relationships with the superiors of caregivers and expected them to intervene on their behalf if they perceived any problem regarding their care. As one of them said, he "went straight to the top" with his complaints (Munn et al. 2008).

The desire to exert influence also referred to making decisions regarding care and treatment in the final stage of their life. Some older persons expressed an explicit *desire to participate in end-of-life decisions* (Kelner 1995; Seymour 2003; Gjerberg et al. 2015)

> Yes, I do want to be part of the decision, along with the staff…. whether or not to be admitted to the hospital. If something happens….with me, I go to the nurses for advice. And they always ask me what I think…. They have to ask me what I think. (Gjerberg et al. 2015)

This implied the *desire to be informed about prognosis and treatment* since information was a prerequisite for decision-making (Hermann 2001; Seymour 2003; Waldrop and Meeker 2014; El-Jawahri et al. 2017).

> I wish I'd known what was going to happen. I knew I had cancer but I didn't know what was going to happen to me. Was I going to be nauseous, was I going to be in pain a lot? They always ask me if I'm in pain and I do have pain pills. Was I going to be throwing up? I would have liked a little more [information]. (Waldrop and Meeker 2014)

Others did not only want to be involved in the decision-making process, they wanted to have the final say and *make end-of-life decisions on their own* (Kelner 1995; Leichtentritt and Rettig 1999; Young et al. 2003; Horne et al. 2006; Ott 2008; Malcomson and Bisbee 2009; Gjerberg et al. 2015; Fleming et al. 2016). For this reasons they welcomed advance care planning discussions on admission to a long-term care facility and were in favour of preparing a living will.

> Advance care planning discussions should be routine questions such as screenings like mammograms and colonoscopies. When somebody is X years old, discussions should begin (Malcomson and Bisbee 2009)

> I would sign a living will if it were in compliance with my wishes. I would sign it. (Ott 2008)

For most of them, end-of-life decision-making implied the *desire to refuse futile treatment* (Kelner 1995; Blackhall et al. 1999; Phillips and Woodward 1999; Wilson 2000; Carrese et al. 2002; Young et al. 2003; Waldrop and Meeker 2014; Bollig et al. 2016; Hirakawa et al. 2017; Yap et al. 2018). According to them, resuscitation and life-prolonging treatment would be unnatural and would make them completely dependent on machines and care from others—which was the condition they absolutely wanted to avoid:

> I don't want to receive life-prolonging means. I want to follow the course of nature… No life-prolonging treatment because what would it lead to? A life without living. (Bollig et al. 2016)

> That means that when you get in that condition they're going to put you on machines to take care of all of your needs even though you may not want it. (Young et al. 2003)

Others went even further and expressed a *desire for a self-determined death* (Kelner 1995; Leichtentritt and Rettig 2000; Baeke et al. 2011; van Wijngaarden et al. 2016a). According to them a good death was a planned death since one could not trust the natural processes to be painless and merciful. Because they believed that being dependent on others was too humiliating, they claimed their right to control their life to its end without interference from others:

> I have a stock of pills at home, and I will use them if I will feel the quality of my life has reached the point in which I do not wish to live any more (Leichtentritt and Rettig 2000).

> It's about freedom. Total freedom. And now I want to keep that freedom, which I've always had, to die in my own way. (van Wijngaarden et al. 2016a)

This perception was not only found among older persons who thought about their dying in advance and who perhaps had no clear idea about the real process, it also existed among those who were actually dying and hoped to escape from their suffering (Dees et al. 2011).

For others, however, the desire to decide about their treatment in the final stage of their life was associated with the *fear that life support would be stopped against their will* (Kelner 1995; Blackhall et al. 1999; Phillips and Woodward 1999; Baeke et al. 2011; Malpas et al. 2014)

> I want to keep on going as long as I can. Sometimes you have to overrule the doctors and do what you think best. (Kelner 1995)

Some of these older persons expressed their concern that the prolongation of life was just a privilege of the rich and was therefore withheld from those who could not afford it:

> If [you] ain't got good insurance they ain't gonna let you stay on. (Blackhall et al. 1999)

> Money talks. If you ain't got no money, you're out. (ibid.)

Others feared that once euthanasia was permitted it would become the rule for economic reasons:

> Where's the dividing line between the next step, where Big Brother comes along and says: Well, okay … very few people over the age of X, let's call it 90, really make a valuable contribution to society; they take up space and they're a demand and even a drain on the health system; we keep on patching them up but they're going to die in a few years' time anyway and that's a waste of money, so let's knock 'em'. Where's the dividing line? (Malpas et al. 2014)

Under such conditions, these older persons were afraid that they had to refuse resuscitation if they were asked about their preferences for end-of-life care (Phillips and Woodward 1999).

Not everyone, however, insisted on the right to have absolute control over such decisions. Some preferred a *joint decision with the family* (Kelner 1995; Thoresen and Lillemoen 2016). Besides, there were many older persons who did not want to exert influence on their end-of-life treatment at all and refrained from making decisions. Some of them believed that it would be best to *leave such decisions to God* (Kelner 1995; Winland-Brown 1998; Carrese et al. 2002; Young et al. 2003; Malpas et al. 2014; Fleming et al. 2016; Lee et al. 2016)

> I've thought about it and I believe that God controls the decision about when your life should end. (Kelner 1995)

Others *expected their family to make such decisions* (Frank et al. 1998; Winland-Brown 1998; Rosenfeld et al. 2000; Seymour 2003; Ott 2008; Malcomson and Bisbee 2009; Bollig et al. 2016; Lee et al. 2016; Hirakawa et al. 2017; Romo et al. 2017; Yap et al. 2018)

> My relatives shall decide for me. (Bollig et al. 2016)

> I know that my son cares about me, and I trust him… if he wants me to live longer, let me have cardiopulmonary resuscitation, if he doesn't want me to suffer too much pain and wants me to pass away, I would also agree with him…he knows which decision is best for me. (Lee et al. 2016)

Even more common was a *desired paternalism*, where older persons expected physicians to make the decisions for them (Kelner 1995; Blackhall et al. 1999; Phillips and Woodward 1999; Rosenfeld et al. 2000; Seymour 2003; Vig and Pearlman 2003; Laakkonen et al. 2004; Ryan 2005; Ott 2008; Gjerberg et al. 2015; Bélanger et al. 2016; Bollig et al. 2016; Fleming et al. 2016; Lee et al. 2016; Hirakawa et al. 2017; Romo et al. 2017; Yap et al. 2018).

> I do not think that I can decide such things. I think this has to be done by the staff (Bollig et al. 2016)

> I perfectly trust the Finnish doctor. I give myself up to the care of the doctor, so I don't really have my own opinions about the treatment. I have always understood that the doctor knows best. (Laakkonen et al. 2004)

Since they felt overburdened with such decisions, they rather desired to be cared for and expected others to make the decision for them. With this attitude, they *simply accepted the decisions of others* without even asking for further information:

> Not much to explain. They just came over and said it was the best thing for me. Switch to hospice and I said that's fine with me. I said as long as I'm taken care of. (Nebel Pederson and Emmers-Sommer 2012)

6.3.2.2 Satisfaction of Exerting Influence on Others

To some extent, home-dwelling older persons felt that they *were in control over their care*.

> It's really nice to be at home. I've chosen to be here. Here I have all my own things and I get help with going to bed and to the toilet. I decide when I want to get up in the morning and I can set my own pace. (Benzein et al. 2001)

Other home-dwelling older persons were less satisfied and told about a *lack of control over their treatment* (Ryan 2005; Devik et al. 2013, 2015; Romo et al. 2017). Having to wait to see a doctor and receiving treatment without getting information and an opportunity to decide about it were the main causes of complaints:

> Much time is spent waiting, and sometimes you feel that time is wasted … There might be other things you would rather like to do. (Devik et al. 2015)

> [They said] the pacemaker would be the most practical way to do it. They didn't really give me a set of options because it pretty much sounded to me like the whole thing was etched in stone. (Romo et al. 2017)

Receiving care at home could also result in *restrictions due to imposed rules and routines* (Nelson-Becker 2006; Andersson et al. 2008; Hanratty et al. 2012; Devik et al. 2015; Romo et al. 2017). Older persons had to accept arrangements made by care providers who sometimes even decided about the furnishings of their home:

> They told me I could come home when they brought a bed in, and I said I don't want a bed downstairs, because there isn't room. Anyway they sent people out while I was in hospital and [my husband] showed them round. And a particular person came and said that it could be done, so eventually they brought this bed […] when I did come home, the nurses came, they lifted me onto this bed, . So and they said they would put me on the bed, and they had to leave me, they couldn't take me off, that was the law, I suppose or something. They just said they had done what they were told to do, and so I would just have to stay, so that was it. (Hanratty et al. 2012)

In other cases, family members began to control their life and prevented them from behaving as they liked. One son, for example, disabled his mother's car while it was still in the garage because palliative patients were not recommended to drive (Nelson-Becker 2006). Such attempts made older persons upset and one man complained:

> My children try and reverse the role, and I am the one that they are taking care of, which is sometimes very aggravating to me. I'm fully aware of what I can and cannot do, and I don't need my children to tell me what not to do. (Romo et al. 2017)

For older persons who had to move to a nursing home or a hospice restrictions were even worse and some of them rather felt imprisoned than being cared for (Franklin et al. 2006; Waldrop and Meeker 2012; Coelho et al. 2016).

> You see … it feels as if they treat us as if we don't understand anything even though we have lived a whole life. […] There is nothing here for us; everything is supposed to be done quickly and fit into the right box. We are told when to eat, when to shower, everything. (Franklin et al. 2006)

> This means a jail. It's a prison to be locked here, a prison (Coelho et al. 2016)

Regarding advance care planning some older persons felt *empowered to decide about their end-of-life care* since they had been informed about their condition and the available options for treatment by their physician or the palliative nurse (Jarrett et al. 1999; Richardson 2002; Horne et al. 2006; Hanratty et al. 2012):

> Ah, I think our talks and discussions and that sort of thing, she has done me the world of good. To be honest with you. You know, in different questions that I asked her and that she asked me and that sort of thing. (Horne et al. 2006)

They were also *confident that their decisions would be respected* by their family and the health personnel (Kelner 1995: Leichtentritt and Rettig 1999; Fleming et al. 2016; Jack et al. 2016).

> I wrote down the way I wish things to happen, what medical efforts should and should not be used in case I will no longer be able to express my beliefs. Now I only have to have faith in my children that they will follow and respect my wishes. (Leichtentritt and Rettig 1999)

Others, however, complained about a *lack of information and participation* in decision-making (Engle et al. 1998; Benzein et al. 2001; Ryan 2005; Andersson et al. 2008; Hanratty et al. 2012; Devik et al. 2013; Ho et al. 2013; Seymour 2003; Waldrop and Meeker 2014; Gjerberg et al. 2015; Haug et al. 2015). In some cases they were excluded from decisions because they were withheld information, in other cases because they did not receive information that they could understand.

> I couldn’t understand a word Dr. said, not a word (Engle et al. 1998)

Some even believed that they would have *no influence at all on their end-of-life decisions* (Kelner 1995; Winland-Brown 1998; Horne et al. 2006; Ott 2008; Malcomson and Bisbee 2009; Lewis et al. 2019) and even if they had a preference for their end-of-life care they feared that their decisions would be ignored by family members or physicians.

> My children don’t get along, and they’ll fight about decisions afterwards anyway – no matter what I decide. (Winland-Brown 1998)

> Often doctors don’t want to let you decide. They’re trained to save people and they have all this fancy technology to use. (Kelner 1995)

In such a system, older persons who wanted to terminate their life felt *deprived of the right to commit suicide*.

> Some potentates in The Hague [city of government] are forbidding you to take your own life [in a dignified way]. You are deprived of your freedom. They make it impossible, at least to do it in a legal way, openly. (van Wijngaarden et al. 2016a)

6.3.2.3 Attention to the Need of Others

Although older persons wanted to exert control on their care, they refrained at the same from demanding care since they *feared to become a burden for their family and friends* (Frank et al. 1998; Fried et al. 1999; Leichtentritt and Rettig 2000;

Rosenfeld et al. 2000; Wilson 2000; Carrese et al. 2002; Chochinov et al. 2002; Vig et al. 2002; Fried and Bradley 2003; Seymour 2003: Vig and Pearlman 2003; Gott et al. 2004; Laakkonen et al. 2004; Lambert et al. 2005; Andersson et al. 2008; Munn et al. 2008; Devik et al. 2013; Ho et al. 2013; Venkatasalu et al. 2014; Haug et al. 2015; Ko et al. 2015; Fleming et al. 2016; Haug et al. 2016, MacArtney et al. 2016, van Wijngaarden et al. 2016a; El-Jawahri et al. 2017; Hirakawa et al. 2017; Eckemoff et al. 2018). Some of these older persons thought that admission to a hospice or a nursing home might offer a solution, while others rather wanted to die quickly to avoid burdening others.

> I don't want anyone to feel that they have to take care of me, so I hope my last period will be short. (Haug et al. 2015)

Those who considered end-of-life care in advance also spoke of their *fear that an artificial prolongation of their life could place an undue burden on relatives* (Blackhall et al. 1999; Young et al. 2003; Lambert et al. 2005; Yap et al. 2018).

> I wouldn't want to be on any kind of life support if it's not going to cure me or if I'm going to be a cripple or a burden to somebody. That is one that I don't want to be, a burden to anybody. (Young et al. 2003)

The same argument was put forward by those who wanted an assisted suicide.

> There's just no reasonable need to wittingly burden others with my misery, is there? My life is completed. (…) It's about preventing myself and my family plunging into misery. It's just unnecessary, so I try to prevent it. (van Wijngaarden et al. 2016a)

At the same time, however, they *feared to burden others with their suicide* and therefore wanted to avoid their assistance:

> I just want to keep it under control. (…) And frankly, I think you shouldn't burden someone else. It's my decision, so I'm fully responsible (ibid.)

In a similar way, other older persons did *not want to burden their families with decisions about end-of-life care* (Phillips and Woodward 1999; Young et al. 2003; Horne et al. 2006; Ott 2008; Malcomson and Bisbee 2009; Baeke et al. 2011; Waldrop and Meeker 2014; Lee et al. 2016; Yap et al. 2018)

> I prefer to make this decision myself, and let it be known that I won't place this burden on anybody's shoulders. In other words, I'm not placing it on any one of my sons or daughters or my wife. Nobody can stand and say they made that decision. (Young et al. 2003)

The *fear of burdening* others did not only relate to one's own family, but also to *caregivers*. It was voiced regardless of the setting where older persons received care. When older persons stayed in a nursing home or a hospital they tried their best to fit in and to avoid unnecessary trouble for their caregivers since they were aware of their workload and restricted time.

> There are people here a lot worse off than me. I don't want to be a bother when someone else needs help more than me, and the girls are so busy. (Cartwright and Kayser-Jones 2003)

For the same reason, older persons *withheld their complaints* when they were not satisfied with their caregivers or felt restricted by roommates (Engle et al. 1998; Devik et al. 2013; Coelho et al. 2016).

6.3.2.4 Satisfaction of Attention to the Needs of Others

Despite their desire not to burden others, older people could not avoid *being a burden* in the final phase of their life. Some felt that their frailty and care dependency caused undue strain on their family, while others were convinced to be just a nuisance (Dees et al. 2011; Rurup et al. 2011; Devik et al. 2013; van Wijngaarden et al. 2015; Fleming et al. 2016)

> I know I'm not supposed to say it out loud, but if I visited my kids, I think they would say: "God damn, it's the old man again." (…) I'm just getting in their way. (van Wijngaarden et al. 2015)

6.3.3 Social Adjustment Versus Unconventionality

6.3.3.1 Social Adjustment

Older persons in the process of dying were not only inclined to pay attention to the needs of others, they also wanted to adjust to social norms and *observe good manners* as long as possible. The ability to control their eliminations was of central concern for them as they had learned in their childhood that this was a requirement for every respectable member of the society (Chochinov et al. 2002; Franklin et al. 2006; Rurup et al. 2011; Lewis et al. 2019).

Adjustment to social norms, however, did not only concern the socially acceptable way of living but also the appropriate way of dying. For example, some members of a Jewish community strove to *die in accordance with social norms*, which meant performing socially prescribed rituals to which they were accustomed.

> I know it does not make much sense, but when the moment of truth arrives, you just do what you know, what you saw in your parents' house, what other people tell you is right. You do not really think in these moments. You just act following what other people claim is right. (Leichtentritt and Rettig 2000)

For older people with a Far Eastern background, social adjustment meant *complying with their family's desire to continue their lives* (Blackhall et al. 1999; Lee et al. 2016). Preserving the life of a sick family member was regarded as the highest duty of the family, to which they also had to succumb—even if they wanted to die. For this reason they rejected advance care planning:

> I am afraid that if I sign these documents without their permission, it will make them feel terrible and angry with me…I need to consider their feelings…it is not right for me to make this important decision by myself without their permission. (Lee et al. 2016).

For religious older persons, the most important social norm concerning death and dying was *observing the taboo of suicide* (Leichtentritt and Rettig 1999; Lambert et al. 2005; Baeke et al. 2011; Malpas et al. 2014). In the studies investigated here this view was expressed by Jews and Catholics, but it is likely to be found in other religious groups as well. As they saw it, life was given by God and human beings had no right to end it according to their own will—even if they suffered from pain.

> That is not allowed. We are not the master of our body. That is not, we are not here for ourselves alone. That is, you ask, I am a little part of God; And I have no power over my body and I am not allowed. (Baeke et al. 2011)

> I believe in God. I believe in the bible. And I believe that God giveth, and God taketh away. Only God giveth, and only God can take away. That is what the bible says and that is what I believe. (Malpas et al. 2014)

While some were very strict in this matter, others said that they understood this desire personally but would still reject it out of moral and religious considerations.

> I think it's okay. But it's not practised in our religion (Baeke et al. 2011)

6.3.3.2 Satisfaction of Social Adjustment

Repeatedly, dying older persons told about their inability to adjust to social norms. This was mainly the case when they lost control over their eliminations. As a result, they *felt ashamed* (Chochinov et al. 2002; Franklin et al. 2006; Rurup et al. 2011; van Wijngaarden et al. 2016a, b)

> What I've got, you know, having the runs all the time, diarrhea all the time, so you're dirtying yourself all the time. And then …, then you feel like a little child, you know. […] and the worst thing of all is that you feel just like a child, inferior. (Rurup et al. 2011)

Another reason for such feelings of shame was a loss of self-control under the influence of morphine, which resulted in a violation of social norms and good manners.

> Like the 4 or 5 weeks that I was on morphine I'm not aware of that time in my life at all… lost it completely. I've seen pictures of myself at the table having Christmas dinner and I don't even remember Christmas. Who was here? And I have a feeling that I might have said something to a couple of people and yet I can't bring myself to ask them if I did… so in that real case, I lost my dignity. (Chochinov et al. 2002)

Older people who rejected suicide because it was against their ideas of social norms gained a sense of *moral satisfaction*. They believed that their death would happen in accordance with moral laws and that they would fulfil their duty to God. Some also hoped to be rewarded in the afterlife.

> When one acts in accordance with one's human nature, everything runs smoothly; as exampled by when one acts in accordance with and drives on the 'agreed' side of the road, all things being equal, everything runs smoothly. When I misuse my freewill to do something that puts me and other people in a conflict situation, I am not really acting rationally. (Malpas et al. 2014)

6.3.3.3 Unconventionality

Regarding the question of ending one's life not every older person was inclined to adjust to social norms. There were also those who *rejected moral taboos* regarding suicide (Leichtentritt and Rettig 1999; Baeke et al. 2011).

> I have troubles with the Jewish perspective towards these issues. I do not think religion should guide the individual at times of reaching end-of-life decisions. What ought to guide our perspectives is what will be most comfortable for the dying patient (Leichtentritt and Rettig 1999)

Knowing that their decision to die voluntarily would meet with resistance in their social environment, they expressed their *desire for more tolerance* regarding their attitude:

> For me to take my life brings shame to the family name. I am aware of that, but I also do not think this family shame should be a factor in making my decisions about death… . What are the consequences of my wishes for the people I care about? If they and everyone else will know that dying in peace is what I wanted, then it should not affect the others attitudes towards my family members. (Leichtentritt and Rettig 1999)

6.3.3.4 Satisfaction of Unconventionality

Due to a social climate that rejected the idea of suicide older persons who wanted to end their lives felt *restricted by social rules regarding death and dying*.

> If there is something that can drive me crazy, it is when the religious people run my life. It happens here all the time […] When I, as a secular person, although being of the majority around here, can't do something I want just because according to their perspective, then it does not correspond with the Jewish beliefs, just because they do not approve of that - this is oppression. When it comes to death and dying, it is most upsetting, as this is one of the issues they have a monopoly over…In case you do not know, they "own" death … They have the "right" to tell me how to die, when, where, how to be buried, what ought to be done in my funeral […] It does not really matter what I say or what my family members' wishes may be. That is what makes the situation so damn frustrating (ibid.)

6.3.4 Closeness Versus Distance

6.3.4.1 Closeness

The desire for social adjustment was motivated by a need for closeness and social contacts, which older persons felt even when their lives came to an end. This need was apparent in their *desire for social participation* (Nelson-Becker 2006; Andersson et al. 2008; Ho et al. 2013; Tishelman et al. 2016). Although they died, they wanted to stay up to date and follow the news. This gave them the feeling of being connected to the world and was the prerequisite for exchanging ideas with others when they came to visit.

> I remain very interested in the world. I want to know what's happening on an international level. As long as I am here, I will keep reading the New York Times. (Nelson-Becker 2006)

Feeling weak and helpless, dying older persons had a need for companionship. It was important for them to *maintain contacts to old friends* (Benzein et al. 2001; Hermann 2001; Andersson et al. 2008; Haug et al. 2015; Coelho et al. 2016; Tishelman et al. 2016)

> It means a lot, almost everything, that you have […] good friends, that you have someone to listen to you and help you when you need it. Obviously it's important for having hope. (Benzein et al. 2001)

Some also *searched for new contacts to like-minded persons* (Benzein et al. 2001; Ko et al. 2015; Warmenhoven et al. 2016). These could be other dying persons with whom they met in self-help groups or just anybody who seemed to understand them.

> The contact group was good because you could talk about whatever you wanted to. They had so many different tumours, in the brain and the liver. You need to talk, although I find it hard, but we were all alike there, all ill in the same way. (Benzein et al. 2001)

Those who stayed in a long-term care facility or a hospice *tried to establish contacts to their roommates*—provided their condition allowed it.

> I went to the dining room for lunch yesterday and I'll try to go today, but other than that I have meals in here. My sister [nurse] said to me to try to [go to the dining room]. I said to sister I want to act normal, just forget about this and mix with people, but it's hard. (MacArtney et al. 2017)

However, more important in such a situation was a *close relationship to the staff*, as it allowed satisfying the emotional aspect of care (Coelho et al. 2016: Mulqueen and Coffey 2017; Lewis et al. 2019).

> Good relationships with the primary health team is what I think is absolutely essential… A good relationship, someone who understands you and understands the family and who will work with other professionals. (Lewis et al. 2019)

The greatest desire, however, was for *close contact with the family* (Benzein et al. 2001; Hermann 2001; Farber et al. 2003; Nelson-Becker 2006; Devik et al. 2013, 2015; Waldrop and Meeker 2014; Haug et al. 2015, 2016; Coelho et al. 2016; MacArtney et al. 2016; Towsley and Hirschman 2018). They dying persons still felt involved in their families' affairs and they were longing for the visits of their spouse and/or their children.

> My family has always been most important to me. The fact that I won't be able to follow and support my grandchildren is really sad. (Haug et al. 2015)

The final meaning of the desire for social contacts in the final phase of life was a fear to die alone and the *wish to be surrounded by familiar persons in the moment of dying* (Engle et al. 1998; Leichtentritt and Rettig 2000; Wilson 2000; Vig et al. 2002; Seymour 2003; Gott et al. 2004; Hirakawa et al. 2017; Munn et al. 2008; Ko et al. 2015; Bollig et al. 2016; Mulqueen and Coffey 2017). These were mainly family members but sometimes also friends or a caregiver of trust.

> Of course I want them (the relatives) to be there when I die. Because this is something unknown … It is not easy for us to be alone then. (Bollig et al. 2016)

> Bad death is being lonely […] I want to have some friends around during my end of life. Friends … at least get a couple of visitors once in a while before I kick the bucket. (Ko et al. 2015)

To be surrounded by familiar persons in the moment of dying, older persons wanted to return to their own home (Fried et al. 1999) when they felt that their time would come and some immigrants also said that they preferred to die in their home country where they expected that their family would care for them.

> My goal is that I want to go back to Khmer [Cambodia] when I am a little bit older. Back home at least when I am sick, I still have my family and my neighbours would come to visit me. The more people come to visit, the merrier. (Becker 2002)

6.3.4.2 Satisfaction of Closeness

The desire for closeness was met to varying degrees. Some older persons told that they still *had contacts to their old friends*, received visits from them, or stayed in touch via the internet (Vig and Pearlman 2003; Duggleby and Wright 2004; Ryan 2005; Andersson et al. 2008; Aoun et al. 2012)

> I do have a few very, very close friends who I talk to them about that [participant's illness] and it helps. And I know that it's between us. (Duggleby and Wright 2004)

Others reported about a *loss of old contacts* since their friends were too sick to visit or they had died already (Andersson et al. 2008; Ho et al. 2013; Fleming et al. 2016). Those who searched for contacts with like-minded persons found their attention and *encouragement* (Benzein et al. 2001; Warmenhoven et al. 2016).

Dying persons who had to stay in a hospital or care facility suffered from feeling of being left out, since they *found no one to talk to* (Andersson et al. 2008). Quite often, however, the desire for closeness was met by the *kindness and attentiveness of staff* if caregivers or nurses took their time, stayed for a chat, and paid attention to their needs (Jarrett et al. 1999; Benzein et al. 2001; Ryan 2005; Horne et al. 2006; Aoun et al. 2012; Devik et al. 2015; Coelho et al. 2016; Hilário 2016; MacArtney et al. 2016).

> I like to be here. They are great! They are very nice! I get along well with all of them. It's a laugh all day! It's a joy! They all like me. I've never been in a place like this and I never saw a place like this. (Hilário 2016)

> Some of them have time to sit and chat… some are able to put themselves in another's place. (Devik et al. 2015)

Some older persons even developed a *close connection to some of their caregivers* who became more a friend than a provider of services (Richardson 2002; Franklin et al. 2006; Devik et al. 2015).

> I really look forward to every visit…I see her as a friend now, not somebody to help me at the last stage of my life. (Richardson 2002)

However, close emotional bonds were restricted to few staff members whose character aroused the sympathy of the older persons.

> There is one who I call Mum … she is so nice and helpful. It's good to meet somebody you connect with. We share the same interest for patchwork. (Devik et al. 2015)

If dying older persons had lost old contacts and could not find new ones *contact to caregivers could become a substitute* that prevented feelings of loneliness. As one older man who lived alone at his home put it:

> The very presence of somebody being there. You know, physical presence, it makes a difference. Psychologically it's a boost… (Jack et al. 2016)

Some older persons also gained a feeling of closeness from a *good relationship to their physician* who was described as attentive and taking his time for some small talk (Haug et al. 2015; Warmenhoven et al. 2016).

On the other hand there were also those whose desire for closeness was not met by caregivers and health professionals and who told about a distanced relationship to staff. As they said, home care nurses just paid a short visit to do their job (Devik et al. 2015) and staff in care facilities had no time to pay attention to their needs let alone to talk to them (Kayser-Jones 2002; Laakkonen et al. 2004; Franklin et al. 2006).

> It is usually a quick visit when they come with my pill dispenser every other week … They can sit down a while if I ask them, but I try not to. (Devik et al. 2015)

> No, nobody here has time to discuss with one individual. (Laakkonen et al. 2004)

The desire for closeness was most satisfied if older persons *had a close relationship with their family* (Chochinov et al. 2002; Vig and Pearlman 2003; Duggleby and Wright 2004; Franklin et al. 2006; Ho et al. 2013; Waldrop and Meeker 2014; Coelho et al. 2016; Warmenhoven et al. 2016; Hirakawa et al. 2017)

> Having a family […] That gives me a lot of cheer. Well it doesn't matter how bad things get. I always know that my family is there and I'm very lucky. Not everybody's family is supportive. But I know that they love me. Yeah, because I belong to somebody and they belong to me. (Chochinov et al. 2002)

Others, however, suffered from a *limited contact to their family* (Franklin et al. 2006; Rurup et al. 2011; Ho et al. 2013). They wanted to see their children and grandchildren more often, but these were too busy and had no time for a visit.

> I wish my son would visit me … but I suppose he is busy and has other things to do. You see, his wife is… I don't really know but they never come here. I wish I had someone to talk to. They never have time for us here, not even to say a word; it's like we are nothing. (Franklin et al. 2006)

Some older persons also *missed the contact with their spouse* because they were widowed or had to leave their partner and move into a care facility (Gott et al. 2004; Ryan 2005; Rurup et al. 2011; Haug et al. 2015). The loss of contact with family and friends could result in a complete *sense of loneliness* (Forbes 2001; Chan and Kayser-Jones 2005; Franklin et al. 2006) that made some of them consider suicide if they were not to die soon (Dees et al. 2011; Rurup et al. 2011; van Wijngaarden et al. 2015).

> Deep inside, you are very much alone. Totally, totally alone. (van Wijngaarden et al. 2015)

For immigrants, a lack of social contacts and ensuing loneliness could result from cultural and communicative barriers in the host countries (Chan and Kayser-Jones 2005) which made some of them desire to return to their homeland when they should be dying (Becker 2002).

6.3.4.3 Distance

Even though older persons felt a need for closeness, they also had *a desire for withdrawal*. Some justified this desire by saying that they needed some rest (Tishelman et al., 2016). For others it was particularly pronounced when they had to be cared for, since at the same time it affected their need for self-concealment (Aoun et al. 2012; Ho et al. 2013; Hirakawa et al. 2017; Mulqueen and Coffey 2017).

> I want to be able to do my own thing and remain in my own room undisturbed. (Mulqueen and Coffey 2017)

6.3.4.4 Satisfaction of Distance

While some dying older persons found circumstances that allowed *enjoying their privacy* (Ho et al. 2013), others had to endure *restrictions of privacy* (Chochinov et al. 2002; Waldrop and Meeker 2014; El-Jawahri et al. 2017). Those living in a nursing home missed their own home, which had protected their privacy and given them the opportunity to withdraw as they pleased, and older persons living at home complained that they had to endure strangers in their private environment.

> All of a sudden, you have six months to live, and you've got these complete strangers in your house who are supposedly going to make you feel better. (El-Jawahri et al. 2017)

6.3.5 Influencing Factors

The emergence of social orientations of action was influenced by the older persons' personal background, and their satisfaction by the attention and care they received as well as other environmental factors.

6.3.5.1 Personal Background

The desire for being cared for in the process of dying was triggered by the need of pain relief and symptom management that resulted from the deterioration of the physical condition—as described in the previous section. If care was not funded by the social system, *lack of financial resources* could prevent older persons from purchasing the desired kind and amount of care, and caused them to worry about burdening their family who finally had to pay for these services (Farber et al. 2003; Nebel Pederson and Emmers-Sommer 2012). *Cognitive impairment* was another obstacle for obtaining necessary care. Kayser-Jones (2002) observed that such residents were neglected by the staff since they were unable to express their needs and to demand help and support.

Attitudes towards advance care planning and the readiness to discuss and decide about this issue depended to some extent on the *socio-economic status* of the older persons. According to Kelner (1995), those who took an active role in the decision-making process were better educated and most of them belonged to the middle class. Education and cultural background could facilitate or prevent *access to information*. Yap et al. (2018) who investigated the perspective of Chinese Australians on advance care planning found that two-third of their sample had not heard of this issue or seen a brochure about it. Some of them thought it was some kind of euthanasia. This lack of understanding was due to their limited knowledge of English. Beside this, personal experiences like witnessing the treatment of other dying persons as mentioned above had of course an influence on the attitude to advance care planning.

6.3.5.2 Care for Social Needs

The satisfaction of social needs depended primarily on the care that dying older persons received. As mentioned above, receiving treatment to relief pain and other symptoms was of major importance. Those who stayed at home also had a feeling of being cared for when they got *domestic support* which included household tasks like bed-making, cooking, or shopping (Aoun et al. 2012; Jack et al. 2016). Beside these practical tasks, *taking time and giving attention* to the older persons' needs were crucial to satisfy the need for closeness and the emotional aspect of care (Jarrett et al. 1999; Benzein et al. 2001; Richardson 2002; Kayser-Jones 2002; Ryan 2005; Horne et al. 2006; Aoun et al. 2012; Devik et al. 2015; Coelho et al. 2016; Hilário 2016; MacArtney et al. 2016). As one older person said:

> That's the difference, the real difference – we get the feeling that they really care (Richardson 2002)

Caregivers who behaved in this way were characterized as *comforting personalities* (Jarrett et al. 1999; Richardson 2002; Horne et al. 2006; Thoresen et al. 2016). Empathy alone, however, was not always enough. Although some caregivers showed great love and care for the dying persons, relatives expressed concern about their lack of knowledge and skills (Cartwright and Kayser-Jones 2003). In order to meet social needs caregivers and nurses were also required to be *competent personalities* who were able to manage difficult situations, provide adequate pain relief, and give appropriate advices (Richardson 2002; Vig and Pearlman 2003; Horne et al. 2006; Jack et al. 2016; Thoresen et al. 2016). Only such persons could reassure the dying:

> It is good to have somebody who has obviously had some training with issues involved with cancer… I don't need to worry about mum when they're here because they would know what to do. (Jack et al. 2016)

Competence, however, did not contribute to the satisfaction of social needs, if care was *restricted to task performance* (Jarrett et al. 1999; Devik et al. 2015)

> The hospice, they're there if you need them but they're only there for pain, aren't they? (Jarrett et al. 1999)

Other older persons complained about the *inattentiveness of their physician* who was not interested in taking care of their symptoms and made them feel that they had to struggle for an examination and treatment (Jarrett et al. 1999; Devik et al. 2013). *Lack of coordination* between caregivers was another reason for feeling neglected (Jarrett et al. 1999; Towsley et al. 2015). If several nurses were involved in providing care they did not share information they had received from the care recipient who consequently had to tell the same thing again and again.

> Different ones all the time don't half get you down 'cos got to explain where everything is, explain all his case history, what needs to be done, every mortal time, show them where all the stuff is out in the kitchen. (Jarrett et al. 1999)

Some older persons also complained about an apparently *useless bureaucracy* that made some nurses to spend much of their time with some documents.

> All the time they have to write everything down don't they and the notes were just building up in the case weren't they? Getting more and more of these notes and every time they came the nurses came on a night time she'd sit there, if she was a different nurse and read all through them. (Jarrett et al. 1999)

Worse than this was *inattentiveness to both physical and emotional needs* as it was observed by Forbes (2001) and Kayser-Jones (2002) and a *withdrawal from the dying* who were left alone in the final moments of their life. The reason for such inadequate care was the above-mentioned shortage of staff which resulted in a lack of time for the dying persons (Forbes 2001; Kayser-Jones 2002; Andersson et al. 2008).

The ability to decide about end-of-life care was diminished if physicians gave *no information about treatment options and advance care planning* (Lambert et al. 2005; Malcomson and Bisbee 2009; MacArtney et al. 2015).

6.3.5.3 Environmental Factors

The satisfaction of social needs was furthermore influenced by environmental factors which also had an impact on the care that dying older persons received. *Suitability of the own home* was a prerequisite to receive care at home. The presence of stairs and upstairs toilets and also poor material circumstances under which some older persons were forced to life were impediments for care at home (Gott et al. 2004). In addition to these material conditions, the *availability of family care* was a prerequisite for staying at home (Jarrett et al. 1999; Wilson 2000; Hanratty et al. 2012; Devik et al. 2013; Waldrop and Meeker 2014). Family members did not only have to give emotional support, they also had to provide hands-on care and to adapt the home to the needs of a care dependent person. Such measures were, for example, using an inflatable paddling pool as a bath downstairs, cutting a hole in a chair and putting a bucket under it to make a commode, constructing night lights, and using a baby alarm to monitor the patient from another room (Jarrett et al. 1999). Due to their involvement, some family members began to assume control over the dying person—even against his or her will.

> She and I fight over whether or not she is going to get the stepladder in the bathroom so she can turn the showerhead down herself. There are certain rules I think - you cannot do that. If you do that I am going to take away some sort of privilege. (Waldrop and Meeker 2014)

Such engagement also led to a considerable *family caregiver strain* (Jarrett et al. 1999; Hilário 2016). Family members suffered from physical and emotional burdens and some even had to quit their job and experienced financial problems.

> I cannot work with my mother in these conditions. I've had to quit my work, I was also exhausted. I didn't feel better even with the medication. I take Cipralex. I take Xanax [both for severe anxiety and panic attacks]. My hands were shaking, my heart sped, I was dizzy. I said: oh my God this is not life! (Hilário 2016)

This situation could be further aggravated if there was no support for care providing family members available (Venkatasalu et al. 2014; Lewis et al. 2019). While under such conditions care at home turned out to be difficult and sometimes required admission to a hospice or another care facility, it was completely impossible if there was *no family* (Wilson 2000; Gott et al. 2004; Hall et al. 2013).

For older persons who stayed in a hospice or another care facility, the desire for closeness was sometimes satisfied when they had *access to the internet* which allowed maintaining contacts to family and friends outside (Tishelman et al. 2016) and when they received *visits from family or friends* (Kayser-Jones 2002; Hilário 2016). Some facilities supported such visits by offering the possibility to accommodate visitors overnight (Tishelman et al. 2016). Visitor friendly rules and regulations also allowed for the *presence of the family at the moment of dying* (Hilário 2016).

Older person's decision-making regarding end-of-life care depended on the role assumed by their family. Some of them had no influence on these decisions and sometimes even did not wish to make them because their *relatives were used to take over decisions* (Blackhall et al. 1999; Bollig et al. 2016; Thoresen et al. 2016). Older persons from China and Korea told that such *decisions would be made according to their culture and tradition* which required family members to conceal a diagnosis and to prevent death as long as possible (Frank et al. 1998; Blackhall et al. 1999; Chan and Kayser-Jones 2005; Yap et al. 2018).

> If my son was informed about my illness, he might either be too worried about my condition or hide this information away from me for fear that I would become too stressed up by the knowledge of my condition. Children are usually like that; they withhold the information out of filial piety to their parents. (Yap et al. 2018)

This attitude made Chinese family members reject hospice care because they believed it would accelerate the death of their relative (Chan and Kayser-Jones 2005). In Western countries, decisions of relatives were not so much determined by traditions but by considerations about what might be the best for the dying person, and this could also be a fast and painless death. To decide, relatives therefore had to rely on their own considerations. Some of them *believed to know the expectations of the dying persons*—even if they had not talked with them about it (Gjerberg et al. 2015; Towsley et al. 2015).

> I know she doesn't want to suffer. She'd rather let go than lie here for a long time in pain. (Gjerberg et al. 2015)

In other cases, older persons had *discussed end-of-life care in the family* or at least wanted to do so since it allowed them to influence the decisions to be made in this case (Ott 2008; Gjerberg et al. 2015; Bollig et al. 2016; Eckemoff et al. 2018)

> I have talked to them about prolonging life. I don't want that. You shouldn't start all kinds of things just to keep going artificially. I said that I wanted to inform them of that. (Gjerberg et al. 2015)

More common, however, was *the avoidance of end-of-life discussions in the family* since both sides considered this issue to be a taboo and did not know how to break it (Seymour 2003; Chan and Kayser-Jones 2005; Ott 2008; Malcomson and Bisbee 2009; Gjerberg et al. 2015; Bollig et al. 2016; Fleming et al. 2016; Lee et al. 2016; Yap et al. 2018).

> I do not dare. We are too afraid to take this up. (Bollig et al. 2016)

> This (advance care planning and dying) is a subject that you do not talk about. (ibid.)

Due to this avoidance, some family members did not know the preference of the dying older persons and were *afraid to make end-of-life decisions* on their behalf (Wilson 2000; Gjerberg et al. 2015; Bollig et al. 2016) which in turn made some older persons fear to burden their relatives with these decisions.

> I do hope that I will not have to make a decision … I do not want to decide. I cannot decide. (Bollig et al. 2016)

Despite such fears, many *family members wanted to be involved in such decisions* since they felt this to be a part of their responsibility for the dying older person (Gjerberg et al. 2015; Bollig et al. 2016; Thoresen and Lillemoen 2016).

> But I think that it is important that one of course will be heard and that one can participate in decision-making when the situation turns up … this should be done in cooperation with the nurses and the doctor. (Bollig et al. 2016)

In some cases, however, *family members were not involved in the decision-making process*. They had no influence on whether the dying person had to be moved to another facility in order to receive better care (Cartwright and Kayser-Jones 2003), and in one case they had not even been informed about the malignant condition of the older person (Kayser-Jones 2002).

6.3.6 Behavioural and Attitudinal Reactions

With the deterioration of their health, dying older persons faced problems to satisfy their social orientations of action. Some of them gave up their desire for self-reliance and *sought for care and treatment* in a hospice or a hospital (Nebel Pederson and Emmers-Sommer 2012; MacArtney et al. 2016). Since receiving care restricted their independence, some also tried to *control caregivers* by complaining about them to their superiors (Munn et al. 2008). On the other hand, some of the older persons who lived at home believed that the best way to maintain control was to *avoid care facilities*, where staff would inevitably enforce their rules (Chochinov et al. 2002; Gott et al. 2004; Hirakawa et al. 2017; Eckemoff et al. 2018).

> If anybody started telling me to do this do that you know, and you've got to be in bed at a certain time and you've got to have help being undressed and all that, I think… God Lord, that… would be the worst thing that could happen. (Chochinov et al. 2002)

In order to satisfy their desire for closeness, older persons who stayed in a care facility *invited family and friends* and some of them also used the internet to remain in contact with them (Nelson-Becker 2006; Tishelman et al. 2016). There were also those who tried to *establish a positive relationship with their caregivers* (Jarrett et al. 1999; Richardson 2002).

Regarding advance directives for end-of-life care, several older persons wanted *to set up a living will or a do-not-resuscitate order* since they rejected a futile prolongation of their life (Kelner 1995; Blackhall et al. 1999; Phillips and Woodward 1999; Wilson 2000; Carrese et al. 2002; Young et al. 2003; Waldrop and Meeker 2014; Bollig et al. 2016; Hirakawa et al. 2017; Yap et al. 2018). Others however preferred *to leave such decisions to others*—either to family members or to health professionals (Kelner 1995; Frank et al. 1998; Winland-Brown 1998; Blackhall et al. 1999; Phillips and Woodward 1999; Rosenfeld et al. 2000; Seymour 2003; Vig and Pearlman 2003; Laakkonen et al. 2004; Ryan 2005; Ott 2008; Malcomson and Bisbee 2009; Gjerberg et al. 2015; Bélanger et al. 2016; Bollig et al. 2016; Fleming et al. 2016; Lee et al. 2016; Hirakawa et al. 2017; Romo et al. 2017; Yap et al. 2018). Those who felt that their situation had become unbearable *searched for assistance to commit suicide* that would allow them to escape from their loneliness and to stay in control of their life (Dees et al. 2011; van Wijngaarden et al. 2015, 2016a).

6.4 The Process of Dying and Identity-Related Orientations of Action

Dying is the ultimate threat to a person's existence, and in their struggle against death older persons tried to maintain their identity. Despite their physical deterioration they still had a desire to work and to relax, a need for diversion and reflection, a concern for others and self-interest, an inclination to self-presentation and self-concealment, and a tendency to a positive and a critical self-perception. Table 6.5 provides an overview over these identity-related orientations of action, their satisfaction, their influencing factors, and the behavioural and attitudinal reactions of the residents.

6.4.1 Work Versus Relaxation

6.4.1.1 Work

Since the dying older persons had been working throughout their whole lives, many of them still had a *desire to be active and busy* when they were in the process of dying (Benzein et al. 2001; Fried and Bradley 2003; Vig and Pearlman 2003; Duggleby and Wright 2004; Ryan 2005; Haug et al. 2015; Tishelman et al. 2016). They continued to do their housework and to pursue their hobbies as much as they were able to do. Some even went on working despite their fatal illness. Being active was self-fulfilment and offered a chance for distraction:

> I think doing all those things will help me to have - live a normal life, you know, as normal as possible with the illnesses that I have. (Vig and Pearlman 2003)

Others, however, were exhausted from their disease and their *desire to remain active disappeared* (Ryan 2005).

6.4.1.2 Satisfaction of Work

To some extent, dying older persons were able to remain active. If they finally lost their energy and were confined to their home or to a care facility, they complained about a *lack of activity* (Kayser-Jones 2002; Ryan 2005; Rurup et al. 2011; Devik et al. 2015)

> I was always so busy, busy, quick, quick. And now you can't do anything, just sit around. Yes, read a bit. I can't even do any handwork any more. My hands can't do anything any more, they can't even thread a needle any more. (Rurup et al. 2011)

For those who had been creative throughout their life, being condemned to inactivity meant *losing the ability to be creative* and this made them feel that their lives had become meaningless (Dees et al. 2011; van Wijngaarden et al. 2016b)

> Not being able to draw and paint is the worst. (…) It feels as though my identity has been taken away. What do I have left? (…) Look, my identity is entirely in art. If you can no longer be active, if you cannot express yourself, then something quite substantial has been taken away. (van Wijngaarden et al. 2016b)

Table 6.5 Identity-related orientations of action, influencing factors, behavioural and attitudinal reactions

Orientations of action and their satisfaction	
Work	Desire to be active and busy
	Desire to be active disappeared
Satisfaction of work	Lack of activity
	Losing the ability to be creative
Mental relaxation	Desire to relax
	Wanting to die in a calm and peaceful way
Satisfaction of mental relaxation	Enjoying the relaxing atmosphere of the care facility
	Comfortable and relaxed when experiencing nature
	Worn out and exhausted from the disease
Diversion	Desire for entertainment
	Desire to have some fun
	Listening to music
	Not feeling the need for entertainment
Satisfaction of diversion	Lack of entertainment
Reflection	Desire for intellectual activities
Satisfaction of reflection	Lack of intellectual stimulation
	Stimulated and distracted by reflection
Concern for others	Wanting to care for the family
	Alleviating the burden (of own death on others)
	Leaving a legacy
	Social engagement
	Willingness to donate organs
	Willingness to become a research object
	Showing care and compassion for roommates
	Desire to reciprocate
	Fear of becoming useless as a mindless body
Satisfaction of concern for others	Feeling useful
	Feeling useless
	Sad that they were unable to prevent sorrow
Self-centredness	Some selfishness
	Losing concern for others
Satisfaction of self-centredness	Feeling relieved of duties
	Self-neglect
Self-presentation	Taking care of physical appearance
	Wanting to be respected as a person
	To be appreciated and remembered after death
	Desire to be honoured in a funeral

(continued)

Table 6.5 (continued)

Satisfaction of self-presentation	Feeling respected by others
	Feeling of leaving a positive memory
	Sure to get a good burial
	Feeling disrespected
Self-concealment	Concealing some memories
	Hiding weakness
	Death as the last means of self-concealment
Satisfaction of self-concealment	Feeling exposed in the eyes of others
Positive self-perception	Efforts to maintain a positive self-image
	Maintaining continuity with the previous self
	Abhorring the idea of vegetating like a plant
Satisfaction of positive self-perception	Positive memories
	Small achievements
	Pride in enduring pain
	Self-esteem enhanced through support of others
	Negative memories
	Loss of self-esteem
Critical self-perception	Willing to recognize weaknesses
Satisfaction of critical self-perception	Loss of the sense of reality
Influencing factors	
Personal background	Functional limitations
	Memory problems
	Socio-economic status
Identity-related care	Showing empathy
	Reminiscence work
	Disrespectful treatment
Environmental factors	Relatives have no interest in biography
	Relaxing atmosphere
	Access to nature
Behavioural and attitudinal reactions	Remaining active
	Seeking relaxation
	Cultivating memories
	Leaving a legacy
	Planning the funeral

6.4.1.3 Relaxation

Given their physical deterioration it was not surprising that dying older persons also expressed a *desire to relax* which to some extent allowed them to recover from exhaustion (Benzein et al. 2001; Hermann 2001; Andersson et al. 2008; Coelho et al. 2016; Hirakawa et al. 2017). Staying in a quiet environment, observing the nature, or just watching people had a calming and soothing effect on them.

> I look out the window, that's the contact I get, so I see them coming there. It is people moving around, because nothing moves in here. No. I like looking at the animals and birds and things like that, […]I sometimes think, it's such fun to look, because I have the time now, because I haven't had the time to look at birds before, but that's what I do. (Andersson et al. 2008)

The desire to avoid stress and exhaustion also concerned the final moment of the older person's life. As they perceived it, dying was a strenuous labour and having already endured much pain, they just *wanted to die in a calm and peaceful way* (Duggleby and Wright 2004; Ryan 2005; Venkatasalu et al. 2014; Bollig et al. 2016; Mulqueen and Coffey 2017). They preferred a quiet environment, free of noise and for this reason some of them rejected to go to a hospital.

> Yes, I would appreciate a calm and natural death. (Mulqueen and Coffey 2017)

> I prefer home. I will not go to the hospital. That is a dangerous place and so crowded. No, no, and no. During the last days any man and woman wants to have a quiet and private place. (Venkatasalu et al. 2014)

6.4.1.4 Satisfaction of Relaxation

Some of the dying older persons told how they *enjoyed the relaxing atmosphere of the care facility* where they stayed. The aesthetic value of paintings, furniture, music, light, and architecture had a calming effect (Tishelman et al. 2016). Others felt *comfortable and relaxed when they experienced nature*—for example, during a walk in the forest or while sitting in their garden (Aoun et al. 2012; Coelho et al. 2016; Tishelman et al. 2016). On the other hand, there were those who could not satisfy their need for relaxation because they felt *worn out and exhausted from their disease*. As one older woman said:

> The cancer illness requires all of me. (Haug et al. 2015)

An older man who received treatment against cancer described the agitation that eventually led to exhaustion in more detail:

> I become easily irritated if I have to concentrate hard on listening to others or when reading. The brain is working with the devilry all the time, so the illness is always in the back of my head. (Haug et al. 2015)

6.4.2 Diversion Versus Reflection

6.4.2.1 Diversion

Despite the sad prospect of dying soon, older persons still had a *desire for entertainment* (Vig and Pearlman 2003; Devik et al. 2015; Tishelman et al. 2016). Entertainment allowed escaping from routines, provided distraction, and chased away boredom also for those who were unable to be active.

> A good day is when something happens, other than what we do every day… something that isn't already organized. (Devik et al. 2015)

Some older persons had an explicit *desire to have some fun*, as it allowed them to combat sadness and depression.

> If I couldn't laugh I think I'd go crazy (Hermann 2001)

Some kinds of entertainment such as *listening to music* were pursued by the dying older persons with passion and they were searched for because of the intrinsic pleasure they could give.

> As far as I'm concerned that's all I want, music, music, music. (Towsley and Hirschman 2018)

And a jazz lover described his passion in the following way:

> It digs up your roots, this jazz music is so programmed in your body so you can't sit still, you feel this rhythm in you the whole time and it's so incredibly wonderful to experience it again (Tishelman et al. 2016)

As with the desire for activity, however, there were also dying older persons who did *not feel the need for entertainment* anymore because of their physical and mental exhaustion.

6.4.2.2 Satisfaction of Diversion

As the statements above suggest, dying older persons could find some entertainment when they were distracted by some unforeseen or exciting event, when they heard or made a joke, or when they listened to music. Others, however, complained about a *lack of entertainment* and suffered from boredom (Devik et al. 2015; Tishelman et al. 2016). Due to their disease, they were confined to their room, could not attend events at the facility, and had to wait for the days to pass. Only occasionally they had a minor distraction.

> Well, there isn't much really. I sit here … and then I get the insulin-injections before every meal… Days pass, strange enough, one like the other. Time feels long. (Devik et al. 2015)

6.4.2.3 Reflection

To some extent, dying older persons also expressed a *desire for intellectual activities* (Tishelman et al. 2016; van Wijngaarden et al. 2016b). Some still wanted to read books to get new ideas and thoughts, while others were yearning for the days when they had visited museums and exhibitions and could share their intellectual interests with their partner.

6.4.2.4 Satisfaction of Reflection

Unfortunately, these desires were not always met and dying older persons complained about a *lack of intellectual stimulation*. One resident in a hospice, for example, was upset by the "crappy magazines" he found in the bookshelves of the facility instead of books that could stimulate his brain and give him new insights (Tishelman et al. 2016). The inability to fully engage with a desired subject such as art was perceived by some older persons as a loss of identity (van Wijngaarden et al. 2016a). On the other hand, older people who had the opportunity to participate in dignity therapy felt *stimulated and distracted by the reflection* that was necessary to compile their biography.

> Well I think it does help you when you can talk to somebody and, you know, it helps to take things away and that… things like the sickness and that, you don't feel, feel about it so much when you can talk to somebody. (Hall et al. 2013)

6.4.3 Concern for Others Versus Self-Centredness

The awareness of their approaching end made older persons think about what really mattered to them in their last days. Concern for others gave purpose to their lives, but it had to be counterbalanced by some self-centredness.

6.4.3.1 Concern for Others

Work and reflection were often motivated by a concern for others. For some older persons, the desire to help others was of particular importance in view of their approaching end. First and foremost they *wanted to care for their family*, and even if they had no strength to do anything for them, they were still worried about them (Laakkonen et al. 2004; Ryan 2005). Their family had been the main focus of their life.

> Anything come up, I was always there. Sickness or whatever, death or whatever, I was there. I never backed away from nobody who was sick. I was always there to help my family. (Ryan 2005)

Some of these older persons had an inclination to be productive, and if they still had the ability to work, they kept themselves busy with producing small gifts for their family (Fried and Bradley 2003). Other older persons had a care dependent spouse and although they were unable to provide care themselves they tried their utmost to support him (Hermann 2001; Haug et al. 2015). If they had children or grandchildren, they were concerned about them and rather than wishing for things for themselves, they had wishes for their future (Hermann 2001; Laakkonen et al. 2004).

> Right now, what gives my life meaning? My life has meaning to the people that I've assisted in growing up, in getting them a start in life. (Duggleby and Wright 2004)

For those considering assisted suicide, concern for their family was the main obstacle for implementing their plan. They believed that family members still needed them and the expected grief of others gave them the feeling of being selfish (Leichtentritt and Rettig 1999; Rurup et al. 2011; van Wijngaarden et al. 2016a, b).

> I cannot leave my family now, they still need me, right now it will not be fair to them. (Leichtentritt and Rettig 1999)

> If they all show the same emotions as my daughter, I don't think I can handle it. Then I'll probably give up my freedom to decide on my own life. Because then I will see so much sadness, I just can't handle that…(…) You hurt someone while it's not necessary, because I don't have to commit euthanasia. No one forces me. (…) It's an escape from all my worries. (…) But in a way, I am abandoning them. (van Wijngaarden et al. 2016a)

In the same way, those who were dying against their will believed that their own death was a fatal blow to those whom they loved, and if they could do nothing to avoid it, they wanted at least to *alleviate the burden* it would cause for them. As one older man told, he had organized his finances and prepared his funeral since he wanted to "see that everything is taken care of, so that everything can be in the hands of my wife, and it'll be an easy transition when I'm gone" (Vig and Pearlman 2003). Furthermore, they wanted to *leave a legacy* for their children—even if it wasn't much (Vig et al. 2002; Duggleby and Wright 2004; Ho et al. 2013; Waldrop and Meeker 2014; Duggleby et al. 2016).

> See that little blue book over there? Something I put together for my kids. This is my heritage. (Waldrop and Meeker 2014)

> I have nothing of value to leave behind for my son and my grandson, but I want pass on to them the values and wisdoms that I have learned through my father and throughout my lifetime…I hope that my advice can help them in their future, making them into strong, upstanding persons (Ho et al. 2013).

Concern for others could also go beyond the narrow circle of the family. Some dying older persons talked about their *social engagement* and their involvement in humanitarian projects—sometimes in the vicinity and sometimes even worldwide (Hermann 2001; Nelson-Becker 2006; Haug et al. 2015, 2016)

> There is a friend of mine […] He is a minister at a church. They are building a new addition to it out there, and I've been going out to help him when I feel like it. It's just being there and helping to give something back for what God has given to me. […] Even if you can't help because of your illness, just talking, just conversation helps. Just knowing that you are giving something to someone else. (Hermann 2001)

> I am involved in an aid project in India. Although I probably won't see it completed, I still feel very inspired and engaged. (Haug et al. 2016)

Some older persons who were asked about their opinion on advance care planning showed an interest in the public welfare through their *willingness to donate organs* or to *become a research object* if they suffered from an incurable disease and some scientists were to try a new method of treatment without any guarantee of success.

> Well, say in cancer…in the case of cancer. If you truly felt it was a terminal case but there was an experimental method that wouldn't necessarily help you but it might help the next person, I wouldn't feel any qualms about them trying it because I would feel like what's the difference for me anyway, you know? (Young et al. 2003)

Some dying older persons who stayed in a care facility also showed *care and compassion for their roommates* (Engle et al. 1998; Franklin et al. 2006; Ho et al. 2013; MacArtney et al. 2017), and even if it wasn't much they could do for them, they at least tried to comfort them.

> I have lived here long enough (nursing home) to see the pains of many other. Knowing that I am not alone and that my sufferings are small and insignificant in comparison, I begin to feel for them…I am beginning to understand the true meaning of humanity. (Ho et al. 2013)

> [I] put my arms around them and told them I loved them, that's all I could do. (MacArtney et al. 2017)

As one older woman explained, caring for others allowed them to continue a role that had given meaning to their life.

> I'm a mother and a grandmother and my whole family is lovely. I help the others at mealtimes. It helps them and the staff. (Franklin et al. 2006)

As for their caregivers, these older persons had a *desire to reciprocate*, because caring for others had always given meaning to their lives.

> I need to be helped by people, but I also want to give back. I want to still be able to help others. (Hermann 2001)

Concerns for others was an essential aspect of being a person. This was also evident in the *fear of becoming useless as a mindless body* in the case of an artificial prolongation of life. The inability to take care of others deprived their existence of its purpose.

> To me you can't contribute anything to society anymore. Okay. You can't think, you are a shell. (Young et al. 2003)

6.4.3.2 Satisfaction of Concern for Others

When dying older persons could help others or do them small favours, they still *felt useful* (Hermann 2001; Franklin et al. 2006; Warmenhoven et al. 2016). This feeling could also arise from simply compiling one's biography for others—as it was done in dignity therapy—or by passing on some wisdom to one's descendants that gave them a better understanding of life (Duggleby and Wright 2004; Ho et al. 2013).

> I feel that I'm not useless, you know … that I am … will help somebody, you know, apart from myself. (Hall et al. 2013)

> And I think a lot of us feel that's why they were put upon this earth was to make a difference in other people's lives. (Duggleby and Wright 2004)

Often, however, physical decline which reduced their life to a struggle to survive and a loss of social participation deprived dying older persons of the chance to do something meaningful for others and made them *feel useless* (Nelson-Becker 2006; Dees et al. 2011; Devik et al. 2013).

> I was a very handy man: there were all kinds of odd jobs to be done in the home for the elderly and I enjoyed doing them. Then I felt useful to this society. I can't do it anymore, I can't do anything anymore. (Dees et al. 2011)

If they still had some abilities to work and do something for others, others' lack of interest in what they had to offer was the reason for their feeling of uselessness, which eventually led them to consider assisted suicide (Rurup et al. 2011; van Wijngaarden et al. 2015, 2016a)

> A few years ago, your children go their own way, and that's good, but then they start forgetting you […] and you notice more and more that the older they get the less interesting you are for them. You want to have contact with them, but they don't want that. So at a certain moment I thought what am I really any good for […] And then you think, well, I might just as well not be here, and yes, that's when those things happen. Then you think, well, why do I really have to stay here. (Rurup et al. 2011)

Older people who still felt needed by others, however, were *sad* that due to their dying they could no longer care for them and *that they were unable to prevent their sorrow* (Chochinov et al. 2002; Gott et al. 2004; Vig and Pearlman 2004; Venkatasalu et al. 2014; Waldrop and Meeker 2014; Fleming et al. 2016; MacArtney et al. 2016). For this reason, some of them did not even want to die at home.

> It is hard to die at home. That is not a good way. If I die at home on the same bed and in the same room, my husband will feel this for the rest of his life. So, it is not a good thing to do. Our children also will feel that their mother died in their house with a lot of suffering. (Venkatasalu et al. 2014)

6.4.3.3 Self-Centredness

Whereas many older persons spoke about their concern for others, mainly their loved ones, others were rather concerned about themselves. They wanted to be relieved of duties and responsibilities in order to have enough time to enjoy their last days. Consequently, they partially or completely abandoned their engagement for others and were now inclined to at least *some selfishness*.

> I have always supported my family. Now I can just enjoy life and let go of the responsibility. (Haug et al. 2016)

Such selfishness was, however, a precondition for concern for others, since those who cannot love their own life and enjoy it are also unable to love the lives of others. This became apparent in the statements of those older persons who had a desire for assisted suicide. As long as they were concerned for others, they felt unable to give up their lives, which implied a certain degree of self-interest. Those, however, who even *lost their concern for others* did not feel inhibited from committing suicide:

> I simply don't have that feeling, because I think: my life is over. (van Wijngaarden et al. 2016b)

Completely tired of living they also had no further self-interest—unless one would interpret their suicide as an expression of it.

6.4.3.4 Satisfaction of Self-Centredness

To some extent, dying older persons were able to free themselves from their sense of responsibility towards others and they *felt relieved of their duties* (Haug et al. 2016). Others, however, went on to be more concerned about others than about themselves which finally resulted in *self-neglect*. One older woman, for example, had ignored symptoms of a tumour in her breast and postponed health examinations since she was afraid that her grandchild would quit his studies if she became seriously ill (Haug et al. 2016). As a result, she was diagnosed too late and received treatment when she was already suffering from metastases.

6.4.4 Self-Presentation Versus Self-Concealment

Dying means to vanish from the consciousness and memory of other persons. Older persons tried to counteract this disappearance of their social identity with a self-presentation that even went beyond their death. At the same time, they tried to conceal aspects of themselves that could disturb the image they wanted to create of themselves.

6.4.4.1 Self-Presentation

Even in the process of dying older persons were still concerned about their self-presentation. Especially women who stayed in care facilities *took care of their physical appearance* (Whitaker 2010). It was important for them that their hair and nails were well tended, that they were well dressed, and that they wore make-up. They wanted to look good and smell nice as long as possible. Older men were less concerned about their physical appearance, but just like their female counterparts they wanted to feel valued and *to be respected as a person* (Chochinov et al. 2002; Farber et al. 2003; Vig and Pearlman 2003; Aoun et al. 2012; Devik et al. 2015; Tishelman et al. 2016). They expected others to show respect for them through their behaviour, which meant that clinicians and nurses did not treat them like a disease, but took them seriously and listened and talked to them.

> You're not a patient, you are first-of-all a person. (Tishelman et al. 2016)

> I guess to me a lot of it would be the respect, the recognizing that you are still an individual that you know.., you're a person whose had a life…you know. I guess it's being treated with respect [that] would probably be a big thing. Being allowed input and taking your requests seriously and your decisions seriously. (Chochinov et al. 2002)

For some older persons, efforts to prolong their life were a sign of such respect:

> People should fight for my life working hard to save life. When they do not let you die easy, it is a sign …It says how much your life is worthy…It says how much they are going to miss

> you, how much you are essential to their life… that your life are important. (Leichtentritt and Rettig 2000)

In case other people should behave disrespectfully towards them, some older men were also ready to defend their social prestige. As one dying nursing home resident said:

> And if he [resident] ever cusses me, he's gonna get it upside the head [with a cane]! (Engle et al. 1998)

Older persons were, however, not only concerned about getting respect when they were still alive, it was also important for them to *be appreciated and remembered after their death* (Leichtentritt and Rettig 2000; Chochinov et al. 2002; Vig and Pearlman 2003; Duggleby and Wright 2004; Ryan 2005; Hall et al. 2013; Ho et al. 2013; Duggleby et al. 2016; Towsley and Hirschman 2018). For this reason, some of them made videos of themselves or wrote down their memories and wanted to leave them as a legacy for their children, while others hoped that their achievements and the way they had lived their lives would have this effect.

> For me to have a good death is to die when I have made some impact on other peoples' lives. If they do not remember a thing, if they did not receive anything from you, then never mind how painless your death was, or how much money you left behind. (Leichtentritt and Rettig 2000)

> That I will continue and be part of my family members lives… that some of the values I believed in will continue to guide them even years after I am gone. (ibid.)

To preserve the memory of the deceased, many cultures have established ceremonies of burial and commemoration, and since older persons wanted to be remembered after their death they had a *desire to be honoured in such ceremonies* (Leichtentritt and Rettig 2000; Becker 2002). This was also a reason why immigrants wanted to return to their homeland before their death, as only there they could expect the ceremonies that met their need for respectful treatment after their death. One older woman from the Philippines, for example, told:

> They really take care of your body there. The dead are really watched. Here they don't. They put the dead person in the morgue and then at 10:00 people have to go home. That's it. It's just the security guard. In the Philippines it's not like that. Even if it's in the chapel. Overnight in the chapel, there are a lot of people that gamble, a lot of mourners, and a lot of people playing mahjong and cards. They do not leave the body or fall asleep while watching the body. […] And then after you are buried, 9 days after that you will again have a gathering. […] And then after 45 days, that means that the soul of the person is going up to heaven, and then you have another gathering. And that is the tradition for someone that dies in the Philippines. (Becker 2002)

6.4.4.2 Satisfaction of Self-Presentation

Dying older persons *felt respected by others* when caregivers or clinicians were attentive to their needs, took them serious, and provided the care they wanted (Chochinov et al. 2002; Aoun et al. 2012; Devik et al. 2015; MacArtney et al. 2016).

In other words, the desire for respect was met, when caregivers satisfied the needs for closeness, care, and exerting influence at the same time. As a home-dwelling older person who received home care said:

> It makes you feel more valued. …and I'm now in the position where I get the help and it feels great. (Aoun et al. 2012)

Older persons who wrote down their memories or had the chance to receive dignity therapy got the *feeling of leaving a positive memory* (Leichtentritt and Rettig 2000; Duggleby and Wright 2004; Hall et al. 2013; Duggleby et al. 2016). Although they would not experience the effects their lives would have on others, they imagined what might happen after their death. For example, one older person who had compiled his biography for his relatives when he received dignity therapy said:

> So it might be useful to have, keep it with my Will … because … people, you know, at a funeral people usually expect somebody to speak about the, the person who's died, don't they … it does contain a good deal of information about my background, you know. (Hall et al. 2013)

What assured them of such expected effects was the experience of how they had been influenced by their own parents after they had died.

> My mother had a good death…She is part of my life, and a strong part of my children's life…It is more than ten years since she died, but they still bring her up… think about what might have been her reactions to their major decisions, like when my son was thinking about leaving the country, getting a divorce. She is still part of our life.(Leichtentritt and Rettig 2000)

For the same reason, those who had planned their funeral in advance were *sure to get a good burial* that would honour them one last time (Becker 2002). On the other hand, there were also those who *felt disrespected and ignored by others* (Chochinov et al. 2002; Vig and Pearlman 2003; Devik et al. 2013; Tishelman et al. 2016). These feelings were due to the treatment they received from clinicians and caregivers which was based on tacit or open ageism.

> Yes, I feel like rubbish. It's like I haven't deserved it (the treatment). I think the doctors ought to listen more to the patients. You can't judge everybody past their seventies to be senile. (Devik et al. 2013)

> Then they [nursing home staff] make you feel like you're a real moron. You know what I mean? They treat you like a little 2-year-old. (Vig and Pearlman 2003)

The loss of old functions, which made older people feel useless, could have the same effect and even trigger the desire for assisted suicide in some of them.

> I simply feel ignored, completely marginalized. You know, in the past, when I went aboard ship, I was the superintendent with full authority, carrying out important work. But now, I feel like a third wheel. Yeah, completely side-lined in all areas. (van Wijngaarden et al. 2015)

6.4.4.3 Self-Concealment

The desire for self-presentation was counterbalanced by a desire for self-concealment. This could be more or less pronounced and usually concerned some aspects of the self that should remain hidden. Older people, who compiled their biographies, ***concealed some of their memories***, which they found disturbing for their self-portrayal (Hall et al. 2013). In a similar way, older persons tried to maintain a façade in order to ***hide the weakness*** that was associated with the process of dying (Vig & Pearlman, 2003; Andersson et al. 2008; MacArtney et al. 2016).

> "Well, the only one that bothers me would be to wind up, you know, incapacitated and lying in a hospital bed indefinitely… That would be the worst scenario that I could imagine […] I wouldn't want my children to remember me that way." (Vig and Pearlman 2003) Since they did not want others to see them in their present condition, they had a tendency to withdraw and avoid social contacts. In the same way, the desire for self-concealment made some of them reluctant to accept care because they felt ashamed.

> "I'm a very, very private person…I don't like anybody touching me, you know, like, showering me." (Aoun et al., 2012)

When their physical decay became too apparent, some regarded ***death as the last means of self-concealment***. Physical decline and dependency was such a threat to their prestige and dignity, that they preferred assisted suicide in order to disappear from life.

> "I prefer to flee. And dying is the best method, as far as I'm concerned." (van Wijngaarden et al. 2016a)

6.4.4.4 Satisfaction of Self-Concealment

Older persons did not always succeed in hiding undesired aspects of themselves. In a number of situations they ***felt exposed in the eyes of others***. Home dwelling older persons made this experience when they used public transport to go to treatment:

> "I don't like talking to strangers. People around here is so noisy. I won't let them see me this sick." (Devik et al. 2013)

In a similar way, some older persons who received treatment in a hospital felt exposed in situations such as being sent for an X-ray in a revealing gown or when a nurse discussed personal details in front of a crowded waiting room (Hanratty et al. 2012). For some, the worst thing of all was that the care they received hurt their feelings of shame:

> "Oh my God, maybe putting me on the toilet seat. These are private things, you know… I still feel like I like my privacy. Even for my sleeping in, it's kind of embarrassing if I'm still sleeping if they come downstairs. You know I've got to be… I've got to be up first and get dressed and be here..." (Chochinov et al., 2002)

6.4.5 Positive Self-Perception Versus Critical Self-Perception

The impression older persons were able to create of themselves in others influenced of course their self-perception. Respect of others encouraged a positive self-perception. The other way round, a positive self-image also supported self-presentation, since confidence in one's own strengths promotes the presentation of positive qualities in interaction with others. Nevertheless, self-presentation and self-perception are not identical. Older person can maintain a positive self-image despite a lack of respect from others, and they can suffer from a lack of self-esteem even though their self-presentation evokes the respect of others. The process of dying is of course a serious threat to a positive self-perception, as it enforces an awareness of one's own weakness. To some extent, however, a critical self-perception that makes dying persons aware of these weaknesses may also have positive effects on their self-acceptance.

6.4.5.1 Positive Self-Perception

In view of their physical decline, dying older persons made still *efforts to maintain a positive self-image* (Benzein et al. 2001; Chochinov et al. 2002; Hall et al. 2013; Duggleby et al. 2016). They set themselves small goals and tried to achieve them or they searched for positive memories in their lives.

> I like to dwell on the past, not in a bad way, just in good things … I didn't have a bad past but especially certain instances that happened, and, and so I, I dwell on the good part. (Hall et al. 2013)

A positive self-perception meant for them to *maintain continuity with their previous self*.

> I guess to me a lot of it would be […] the recognizing that you are still an individual that you know… you' re a person who had a life…you know. (Chochinov et al. 2002)

They were afraid that their physical deterioration might put them in a state they could no longer reconcile with their desired self-image. This fear was already evident in advance care planning when many older persons rejected artificial prolongation of their life since they *abhorred the idea of vegetating like a plant* and being completely dependent on the help of others (Blackhall et al. 1999; Rosenfeld et al. 2000; Young et al. 2003; Lambert et al. 2005; Ott 2008; Bollig et al. 2016; van Wijngaarden et al. 2016a, b; Romo et al. 2017; Yap et al. 2018). This condition was not compatible with their self-esteem. Just being there without having a will of their own deprived them of what it meant to be a person. Some of them had seen others in such a condition:

> Well, they had… as far as I understand they had the… she took … she was all blown up and they had her hooked to machines. She just lay there, knew nobody. The doctors said she wasn't feeling anything. She didn't know what was going on. She was just like a vegetable lying there. That was it. (Young et al. 2003)

With such an outcome of medical treatment in mind they concluded:

> I don't want to be reduced to an insane, idiotic zombie lying in his own dirt. (van Wijngaarden et al. 2016a)

6.4.5.2 Satisfaction of Positive Self-Perception

Some dying older persons gained a positive self-image through *positive memories* of beautiful moments or achievements in their lives (Andersson et al. 2008; Devik et al. 2013; Hall et al. 2013). One older woman, for example, recalled her motherhood.

> I have three children, yes I have and that is something to be proud of and it's me that has done it and no one else, raised them, they are both fine and nice. (Andersson et al. 2008)

Others needed the help of therapists to promote their reminiscence as it is done in dignity therapy and similar approaches. Inspired to think about their former lives, they found memories they cherished.

> It makes you think a little more about the good things you do have. Uh, yeah, just the good things you do have. It's easy to focus in on the bad, so even a moment of reprieve, of thinking about good stuff, is - is nice. (Duggleby et al. 2016)

Small achievements in performing everyday tasks were another source of self-esteem.

> Well I really achieved something, I made some muffins the other day for us, and I haven't baked for months. (Duggleby and Wright 2004)

Older persons in a palliative care facility in Hong Kong had another way to gain a positive self-perception. They took *pride in enduring their pain* as this was considered a virtue in Chinese teachings from Buddhism and Confucianism (Ho et al. 2013).

There were also those who told how their *self-esteem was enhanced through the support of others*. Receiving care could have this effect, since it was also a sign of respect from others that could boost a positive self-perception:

> The care aide really boosts me up – she's brilliant! She makes me feel better…Ooh, a lot of benefits [care aides]. My whole esteem is gone up and I feel like the needs, that someone cares, you know, not just your family. (Aoun et al. 2012)

On the other hand, there were older persons who were plagued by *negative memories* which prevented them from gaining a benefit from reminiscence (Hall et al. 2013; Duggleby et al. 2016). More often, however, dying persons suffered from a *loss of self-esteem* due to their increasing physical deterioration and the ensuing decline in functional abilities (Duggleby 2000; Benzein et al. 2001; Chochinov et al. 2002; Ryan 2005; Franklin et al. 2006; Whitaker 2010; Dees et al. 2011; Rurup et al. 2011; Coelho et al. 2016; van Wijngaarden et al. 2016b). They were still attached to their former self, but they could not find it in their present self-perception, and therefore felt alienated from themselves.

> I used to be known to be strong with my hands. People would ask me to open things for them, bring them to me. I could open the tightest jar, bottle, or anything there was and now… it's a big letdown. I feel like I've gone from being a king to being a pauper. I didn't even want to carry a cane up there for a long time. It would have helped me but, and a wheelchair was clear out of the notion. I just felt like I was too good to ride in a wheelchair. I know that is not right. It [cancer] just knocks you down to where you feel like you could crawl underneath the door. You lose all your self-respect [tearful]. […]That is just not my style of living. (Ryan 2005)

For some older persons, the experience of their physical decline triggered the desire for assisted suicide (Dees et al. 2011; van Wijngaarden et al. 2016b).

6.4.5.3 Critical Self-Perception

Although a critical self-awareness in the process of dying can result in a loss of self-esteem, a one-sided pursuit of a positive self-image would prevent a true knowledge of the self. This was, however, important for older persons who had reason to consider their life as failed, such as those who were homeless. Some of these persons were therefore *willing to recognize their weaknesses*. They believed that overcoming them would help them to find a peaceful death.

> I express [anger] inappropriately. It's anger towards myself, but I've been expressing it inappropriately … I'll be locked back up again. It could very well cause an unpleasant death. (Ko et al. 2015)

6.4.5.4 Satisfaction of Critical Self-Perception

As the statement above suggests, critical self-perception offered the chance to improve one's character, which would ultimately result in a better death. There were also instances where dying older persons lost their critical self-awareness. The use of morphine created a positive mood, which, however, was illusory and prevented a realistic self-perception. When the effect of the drug diminished and older persons regained consciousness, they were not sure about what they had done and regretted the *loss of their sense of reality* (Chochinov et al. 2002).

6.4.6 Influencing Factors

6.4.6.1 Personal Background

The fulfilment of identity-related orientations of actions depended on the personal background of the dying older persons. *Functional limitations* prevented them from working and from showing concern for others. They also restricted their abilities for self-representation and contributed to a negative self-image. Sometimes physical decline was associated with *memory problems*, for example, when older people had suffered a stroke. This could impair attempts to promote their self-esteem through biographical work.

> I don't remember much about it [dignity therapy] now, but I do remember it, yes … quite honestly I don't know what the document was about now [laughs] it's too long ago, so … After all, at my age … you can remember sort of some things and that, but things like that you just answer them and then they've gone. (Hall et al. 2013)

The desire for self-presentation and the possibility of satisfying it depended furthermore on the *socio-economic status* of the older persons, which—as mentioned above—also influenced their chance to be cared for as desired. The same concerned their options to leave a heritage and to prepare their funeral.

6.4.6.2 Identity-Related Care

The care that the dying older persons received had also an effect on how their identity-related needs were met. If nurses and caregivers *showed empathy* and treated them with respect, they could promote older persons' self-esteem (Chochinov et al. 2002; Kayser-Jones 2002; Aoun et al. 2012; Devik et al. 2015; MacArtney et al. 2016). Such a caring behaviour consisted of being polite, listening, responding to their needs, and doing small favours. Some facilities also made attempts of *reminiscence work*. Examples of this are dignity therapy (Hall et al. 2013) as described in the previous chapter or the Living with Hope Program (Duggleby et al. 2016) which consisted of viewing a short 12-minute film showing terminally ill persons and their family members talking about how they maintain their hope and beginning a hope activity over a one week time period like writing letters to someone (either alone or with help of someone), beginning a collection of poems, writings, pictures, photographs, and music, or telling a story about one's own life that was written down or audiotaped. On the other hand, there were facilities that had no time for such activities and where the high workload of the staff resulted in a *disrespectful treatment* of the dying persons (Kayser-Jones 2002).

6.4.6.3 Environmental Factors

The desire for self-presentation and self-esteem was also influenced by the social environment of the older persons. Sometimes they had no closer family and they felt that their remaining *relatives had no interest in their life story*.

> Well I haven't got a family, you see … well they're not immediate [siblings] … they might not like it, because I've referred to them here and there, and maybe they'd prefer not to be. So it's … it's a bit awkward … it'd be up to them how they view me, of course. Some might be, say, well that poor old devil had a hard time, and others will say, oh he must have been a lazy old bugger to spend his life like that, you know … Well they probably wouldn't be in the least interested. (Hall et al. 2013)

By contrast, a beneficial factor for the satisfaction of their identity-related needs was the *relaxing atmosphere* that existed in some care facilities (Tishelman et al. 2016). *Access to nature* by staying in a garden or other outdoor activities had a similar effect (Aoun et al. 2012; Coelho et al. 2016; Tishelman et al. 2016).

6.4.7 Behavioural and Attitudinal Reactions

In order to satisfy their identity-related needs, dying older persons tried to *remain active* as much as possible (Benzein et al. 2001; Fried and Bradley 2003; Vig and

Pearlman 2003; Duggleby and Wright 2004; Ryan 2005; Haug et al. 2015; Tishelman et al. 2016). Due to their declining energies, they increasingly *sought relaxation* as a means of compensation (Benzein et al. 2001; Hermann 2001; Andersson et al. 2008; Coelho et al. 2016; Hirakawa et al. 2017). In order to maintain or regain a positive self-image, they *cultivated their memories*—either alone or by participating in a reminiscence programme, as offered by some facilities (Andersson et al. 2008; Devik et al. 2013; Hall et al. 2013; Duggleby et al. 2016). *Leaving a heritage* was a way to show concern for others that met at the same time their desire for self-presentation (Vig et al. 2002; Duggleby and Wright 2004; Ho et al. 2013; Waldrop and Meeker 2014; Duggleby et al. 2016). The *planning of the funeral* could also serve the latter purpose (Leichtentritt and Rettig 2000; Becker 2002).

6.5 The Process of Dying and Development-Related Orientations of Action

Dying is a confrontation with the unknown. Religions give different answers to the question of what might be after death, but these answers are a matter of belief and there is no certainty that there will be anything at all. Even religious persons are afflicted by doubts. Since dying is a transition from the known to the unknown, the awareness of approaching death causes fear. The process of dying is the final development a person has to go through, and as such, it affects all development-related orientations of action. It questions the tendency to maintain old habits and makes it impossible to search for new perspectives. Instead, older persons have to think about completing their life story, and they may react to their impending death by denying it or facing it, and by inclining to scepticism or hope. Underlying the whole process of dying, there is, however, a further balance between an attachment to and a detachment from life that shifts slowly from the former to the latter. In the previous chapters, this balance has remained unnoticed, since attachment to life is the natural and taken for granted orientation of every person. It is only in the process of dying that a tendency to detach from life becomes apparent which counteracts the natural attachment to life. Therefore, the model of the orientations of action in the process of dying has to be supplemented by these two tendencies. The complete model is shown in Fig. 6.2, and Table 6.6 provides an overview over the development-related orientations of action, their satisfaction, their influencing factors, and the behavioural and attitudinal reactions of the residents.

6.5.1 Attachment to the Past Versus Completing the Life Story

Even when life comes to an end older persons are connected to their past. Their past life is their identity and in the face of impending death it becomes meaningless to search for new perspectives. In the previous chapters, a search for new perspectives meant a conscious turn to new challenges and experiences in order to escape from the stagnation of a life determined by habits and routines. In the process of dying,

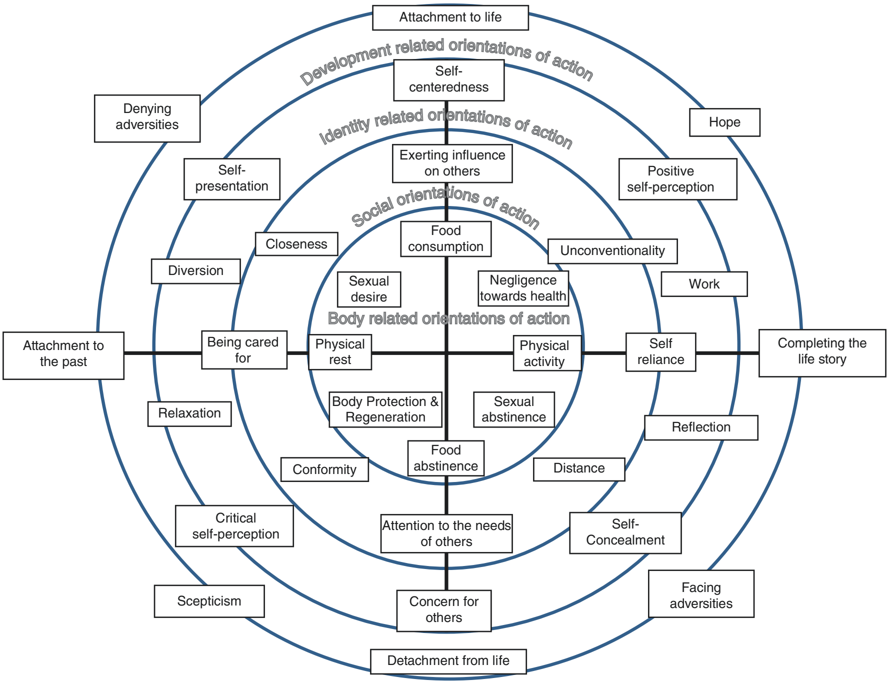

Fig. 6.2 The complete model of orientations of actions

however, the challenge is not to search for something new and unknown, because impending death, although unknown in its reality, is not a challenge that could be mastered. It is not something new to be learned or a task to be accomplished. Death concerns life as a whole and forces the dying person to reflect on him or herself. The whole life becomes an open issue that makes the dying person aware of his or her imperfection. What then remains to be done is to solve unresolved issues in order to complete the story of one's own life.

6.5.1.1 Attachment to the Past

The process of dying called old habits into question, but older persons wanted *to maintain their life as usual*—at least as long as they were able to do so. Some even claimed that there was no big difference to their previous life except some restrictions.

> [Life is] not much different, yeah it's just going on as normal yeah, except I'm a bit tired and I'm not playing golf as much as I had. (MacArtney et al. 2017)

Their attachment to the past was also evident in their *desire to stay in a familiar environment* when death approached. For home-dwelling older persons this meant to remain at home, because they felt rooted in their own place and had the chance to be surrounded by family members or friends when their final moment of life

Table 6.6 Development-related orientations of action, influencing factors, behavioural and attitudinal reactions

Orientations of action and their satisfaction	
Attachment to the past	Maintaining life as usual
	Desire to stay in a familiar environment
	Surrounding themselves with memorabilia
	Cultivating memories
	Attachment to cultural heritage
	Wanting to return to the home country
	Less interested in own memories
	Not important to die at home
	Detached from homeland
	Getting rid of memories
Satisfaction of attachment to the past	Feeling comfortable at home
	Feeling at home in the care facility
	Reliving the past
	Dying in the homeland
	Sadness over loss of past lives
	Not feeling at home in the care facility
	Not feeling at home in the own home
Completing the life story	Bringing life to a good end
Satisfaction of completing the life story	Discovering the hitherto unrecognized quality of life
	Open issues
	Having achieved everything they wanted in their lives
Attachment to life	Desire to life
	Fear of death
	Opting for life prolongation
	Rejecting euthanasia
	Less resolute in demanding prolongation of life
	Unable to make a decision regarding advance care planning
	Wish to be cured and to survive
	Desire to prolong life in the process of dying
	(Rejection of) hospice as a warrant of death
Satisfaction of attachment to life	Getting treatment
	Breakdown of resilience
Detachment from life	Preferring death instead of useless suffering
	Caught between the desire to live and to die
	Longing for death to escape from hope
	Losing the desire to live
	Wish for assisted suicide
	Torn between a desire to live and a desire to commit suicide
Satisfaction of detachment from life	Being able to accept the end in a calm and serene way
	Being unable to die or not having died in time
	Plagued by fear of a failed attempt at suicide

(continued)

Table 6.6 (continued)

Denial of adversities	Avoiding to think about death
	Avoidance of advance care planning
	Desire not to know the truth
	Unwillingness to believe that death is approaching
	Not thinking about and distracting oneself
	Wanting to die without noticing it
Satisfaction of denial of adversities	Temporarily feeling good
	Depression after conversation about advance care planning
	Shock when hearing diagnosis
	Fears and worries during treatment
	Having to accept the admission to palliative care
Facing adversities	Theoretically confronted with death
	Ready to talk about advance care planning
	Torn between the desire for truth and the desire for denial
	Gradually giving up the denial
	Desire for the truth
	Desire for a conscious death
Satisfaction of facing adversities	Feeling deceived
	End to uncertainty
	Coming to terms with death
	Death as the normal end of life in the facility
	Overcoming fear from palliative care
	(Finding the) chance to plan the last steps
Scepticism	Atheism
	Downsizing expectations
Satisfaction of scepticism	Feeling free from delusion
	Finding equanimity
Hope	Searching for a sense of hope
	Trying to think positively
	Downsizing the trouble in one’s mind
	Focusing on smaller goals
	Trying to live in the present
	Daydreaming
	Religious expectations
Satisfaction of hope	Loss of hope
	Loss of faith
	Feeling of inner strength and assurance
	Enjoying the moment
	Inner peace
	Accepting death as a part of life
	Religious or spiritual consolation

Table 6.6 (continued)

Influencing factors	
Personal background	Trajectory of dying
	Previous experiences
Environmental factors	Cultural denial of death
	Cultural change regarding death and dying
	Death as a cultural event
Development-related care	Institutional denial
	(Advance care planning as an) administrative act
	Inattentiveness to needs
	Insensitive communication
	Sensitive communication
	Sessions to discuss death and dying
	Dealing with death in an open way
	Allowing to create a homelike atmosphere
	Giving comfort
Behavioural and attitudinal reactions	*(same as development-related orientations of action)*

approached (Frank et al. 1998; Wilson 2000; Seymour 2003; Gott et al. 2004; Andersson et al. 2008; Venkatasalu et al. 2014; Waldrop and Meeker 2014; Devik et al. 2015; Fleming et al. 2016; Jack et al. 2016; Hirakawa et al. 2017; Mulqueen and Coffey 2017; Lewis et al. 2019)

> I want to stay in the house that I built until the very end of my life. (Hirakawa et al. 2017)

The comfort and familiarity of the own home was often contrasted with the anonymous and sterile atmosphere of the hospital which was despite better options to receive medical care a less preferred place to die.

> The hospital has to be the last place on earth in any country that you would need to go simply to die. (Lewis et al. 2019)

Not surprisingly, older persons who had to stay in a care facility expressed their desire to return home (Kayser-Jones 2002; MacArtney et al. 2016)

> I said to my husband 'I want to get home, I want' – I know it's going to sound silly, but we've been married over 40-odd years and I miss him being with me in bed. I know it sounds silly, and I just miss him … He said 'I want you to come home', I said 'so do I' (MacArtney et al. 2016)

For some residents, however, the care facility had become their familiar environment, and staying there to die seemed at least to be better than going to the hospital (Cartwright and Kayser-Jones 2003; Bollig et al. 2016). A desire for a familiar environment was also apparent among homeless older persons, who hoped to be admitted to a facility with a familiar social atmosphere, as it was mentioned by a veteran:

> I may not have a specific place to go, however, the places surrounded by veterans … could share the same experience with you … We have that in common. And that's a very intensive relationship. I've met people over the years and … I go to support groups there. And … I feel comfortable around veterans. (Ko et al. 2015)

Older people who had moved into a hospice or a care facility tried to connect to their past by *surrounding themselves with memorabilia* (Hilário 2016; Mulqueen and Coffey 2017; Tishelman et al. 2016). In many cases, these were photographs of family members or former possessions that were hanging in their room, but there were also some older persons who used a computer screen for this purpose:

> I just put in a screen shot from the entrance porch at home … when I open the computer I see it, and that's the case when we come home also, it's the first thing we see … even from inside the house. (Tishelman et al. 2016)

Regardless of where they lived, older people tried to keep a connection to their past by *cultivating memories*—either by reviewing their life alone or by sharing their memories with others (Benzein et al. 2001; Hermann 2001; Franklin et al. 2006; Nelson-Becker 2006; Andersson et al. 2008; Duggleby et al. 2016; Warmenhoven et al. 2016; Towsley and Hirschman 2018). As mentioned above, such reminiscence also promoted a positive self-perception in the face of declining abilities. For immigrants, attachment to the past implied an *attachment to their cultural heritage*. When they died, they wanted to be treated and buried according to their own traditions. An old man from India, for example, said:

> We shouldn't forget our culture. It should go through all the generations. At the end of the day, it is our culture. We can still respect our culture even if we are not in our own country, so that we won't lose our culture. Then we wish we could send our ashes back to India. (Venkatasalu et al. 2014)

Muslims and Christians expressed the same desire which often implied a desire to remain at home as it was the custom in their home country.

> A true Muslim should die at Mecca, or Medina, and facing east. The Day of Judgment comes there. If it is not possible, then he should die at home with his family around him. And also, dying on a Friday is considered to be a good death. People say it is a blessed death (ibid.)

> I want someone to be near me so they can pray. But it won't happen if we die in hospital. […] I would prefer to die in a nice way, and be with someone who can pray to Jesus. I need someone to whisper prayers in my ears. In our community, we call the priest. That is very important in our religion. (ibid)

To meet this desire, several older persons *wanted to return to their home country* when the time of their death would come (Becker 2002; Venkatasalu et al. 2014).

> I would like to die in Bangladesh. May God prove my wish? Definitely I love to die on my own Bangladeshi soil. Yes I am British. This is my country as well. But I was born in Bangladesh. I came to this country during my adulthood. I adopted this country. I love this country as well, but for my death, my own village will be the best place to die. (Venkatasalu et al. 2014)

As we saw above, a funeral at their place of origin would also satisfy their wish to be honoured in a final ceremony.

However, not all older persons had such a strong attachment to the past and to traditions. Some were in fact *less interested in their memories* and needed a motivation to reminisce when they were enrolled in the above-mentioned Living with Hope Program (Duggleby et al. 2016). Reminisce was apparently something they were not used to. For others it was *not so important to die in their own home* as they were not strongly attached to this place (Fleming et al. 2016), and as for the immigrants, there were also those who were internally *detached from their homeland*. As one of them put it:

> My family is settled here, so why should we go back? (Venkatasalu et al. 2014)

Finally, there were also older persons with the intention to die, who tried to *get rid of their memories*. They threw away stuff that was no longer needed, and tore up photographs, letters, and other documents. As one of them explained:

> It's a way of making your place empty. (van Wijngaarden et al. 2016a)

6.5.1.2 Satisfaction of Attachment to the Past

Older persons in the process of dying could satisfy their attachment to the past to varying degrees. Some had the chance to remain at home and to receive home care. Surrounded by a place that was connected with so many memories, they *felt comfortable at home* (Benzein et al. 2001; Devik et al. 2015). Others who had to leave their old home achieved a sense of *feeling at home in the care facility* because they were able to follow personal routines and had at the same time a sense of security as there was always someone nearby to help them (Andersson et al. 2008; Tishelman et al. 2016). Those who reminisced *relived their past* in their memories (Devik et al. 2013; Tishelman et al. 2016). Sometimes such memories were evoked by images, as in the case of a hospice resident who relived the dancing events of his youth at the sight of a poster for an in-house entertainment (Tishelman et al. 2016).

As for the immigrants, some of them succeeded in returning home before they died. An older woman from the Philippines, for example, told how she could fulfil her husband's wish to *die in his homeland*:

> The doctor said that I could not bring my husband home to the Philippines because he can't get on the airplane. Because he was already in a wheelchair. I told him that I had to. I asked if the doctor could give us a certificate so that if something happened while we were on the plane then I could show someone the certificate. He gave me one. We left at 6:00 in the evening from our apartment, and I brought him home to the Philippines on the plane. I was able to buy a ticket. And then I took him on the plane. With the mercy of God no one asked us, "What's wrong with your husband, is he sick?" Because he looked strong. When we got to the Philippines, on May 4, at 3:00 he died [a few days later]. He was so happy to see his kids, that he was very happy when he died. (Becker 2002)

Not everyone, however, was able to remain connected to his past. Physical decline forced dying older persons to abandon old habits and they suffered from *sadness over the loss of their past lives* (Farber et al. 2003; Ryan 2005; Devik et al. 2013; Haug et al. 2015). Likewise, there were older persons who had to move into a hospice and did *not feel at home in the care facility* (Franklin et al. 2006; Andersson et al. 2008; Tishelman et al. 2016).

> I don’t know why, but for me it’s not home… a home environment, it’s not that. (Tishelman et al. 2016)

But also some of those who received care at home complained about *not feeling at home in their own home*. Assistive health technologies brought in by the hospice nurses changed the character of their home into a hospital.

> We reached a stage where this hospice at home took over and they just literally moved all the equipment that they needed to look after [husband]. Erm, it was just like him being in hospital. (Gott et al. 2004)

6.5.1.3 Completing the Life Story

In view of their approaching end, dying older persons had no future prospects that allowed searching for new perspectives. What remained to be expected for them was to complete open issues in order to *bring their lives to a good end* (Leichtentritt and Rettig 2000; Benzein et al. 2001; Hermann 2001; Vig and Pearlman 2003; Ryan 2005; Coelho et al. 2016; Towsley and Hirschman 2018). They wanted to say goodbye to their families and friends, make their funeral arrangements, and complete unfinished business.

> Saying good byes, not having death happen before I will have a chance to separate from all the people. (Leichtentritt and Rettig 2000)

> I wish to have enough time to sort through my things, give what I wish people to have from me, and throw other things away…I do not wish anyone else to have to do that for me after I am gone. (ibid.)

Some older persons felt that there were still unresolved issues that prevented them from finding peace before dying. They had feelings of guilt and wanted to reconcile with those who were close to them (Hermann 2001; Farber et al. 2003; Ko et al. 2015)

> I’d tell them how much I love them, you know … tell them if I did… forgive me if I did something wrong … Express my feelings and say I love them. (Ko et al. 2015)

6.5.1.4 Satisfaction of Completing the Life Story

Reminiscence could also be a way to complete one’s life story. Some older persons who did so became aware that they had been inattentive to many positive things in their life and they *discovered the hitherto unrecognized quality of their life.*

> I lost too much time scolding my family…and today I can only think of that everything we lived was wonderful… We don’t regard things until they are lost. (Coelho et al. 2016)

Rethinking the past through reminiscence did, however, not always result in a rediscovery of positive experiences. Sometimes older persons were confronted with *open issues* they were unable to finish.

> Here we think about everything, we weigh everything, and here some things are left to be concluded and others left halfway. (Coelho et al. 2016)

Others, however, felt that there were no unresolved issues and that they *had achieved everything they wanted in their life* (Leichtentritt and Rettig 2000; Vig and Pearlman 2003; Lambert et al. 2005; Warmenhoven et al. 2016). Hence, there was no further need to search for new perspectives.

> I've lived a full life, you know. And I think I've done about everything I wanted to do, been everywhere I wanted to go. (Vig and Pearlman 2003)

6.5.2 Attachment to Life Versus Detachment from Life

Attachment to life is the tacit desire that underlies all other needs and desires. It only becomes apparent when people are confronted with the possibility of death. Even when people are dying, they struggle for survival, and it is this attachment to life that makes the process of dying a painful experience. A detachment from life can therefore bring relief. But there are also older persons who are tired of life. Contrary to the common attachment to life, they are inclined to an extreme detachment from life and want to commit suicide.

6.5.2.1 Attachment to Life

When older persons were asked about their idea concerning the end of their lives, they usually expressed a *desire to live*—at least for a slightly longer period of time (Fleming et al. 2016; Towsley and Hirschman 2018).

> Like I feel now, I wouldn't want to die because I feel all right. (Towsley and Hirschman 2018)

> I can still enjoy the food. I'm gonna be around another year maybe… I don't want to be just lying in bed doing nothing. Give me one more year and that's all I want. Because I still think I can enjoy things for one more year. After that the bad will outweigh the good. It's a balance (ibid.)

Underlying this desire was the *fear of death,* which concerned both the idea of one's own non-existence and the painful process of dying (Engle et al. 1998; Leichtentritt and Rettig 2000; Chochinov et al. 2002).

> I am not afraid to admit—Yes, death, the finality …It makes me upset … Just thinking about this whole issue raises my blood pressure! (Leichtentritt and Rettig 2000)

> Death is always a difficult thing, a painful process …We can talk about my wishes regarding how to ease the process, make it less painful, less difficult … but death is not something good (ibid.)

Given this fear of death, it is not surprising that there were several older persons *who opted for life prolongation* when they were asked to think about advance care planning and they disliked the idea that a physician might decide to terminate their lives by ceasing treatment (Kelner 1995; Winland-Brown 1998; Blackhall et al. 1999; Phillips and Woodward 1999; Leichtentritt and Rettig 2000; Towsley and Hirschman 2018).

> If the doctors can keep me alive for 200 years, I'll accept it. Thar's how much I'm scared of death. (Winland-Brown 1998)

> I would want to be put on a machine and be here as long as possible … I believe in a power greater than man … a miracle or whatever. (Blackhall et al. 1999)

For the same reason, some older persons *rejected euthanasia* to alleviate suffering (Seymour 2003; Baeke et al. 2011; Bollig et al. 2016). According to some of them, a discontinuation of treatment was also unacceptable on ethical grounds, since a decision about life and death should not fall within the responsibility of a human being.

> I would not want to be the authority who says 'that person has the right to wake up' or 'it is enough for us, we spent enough money' (Baeke et al. 2011)

Others feared abuse if doctors were allowed to hasten death and referred to cases where physicians had been convicted for killing older persons with diamorphine (Seymour 2003). Some older persons raised similar concerns about advance care planning. They believed that the possibility to decide such matters would make people choose what was in the interest of others but not in their own.

> People might feel that they're going to be a drag on their family, a lot of old people do, and this might pressure the patient into making a decision not to be resuscitated. (Phillips and Woodward 1999)

However, since it was expected that dying would be a painful process, others were *less resolute in demanding a prolongation of their lives*. They only a wanted it if there seemed to be a reasonable chance to restore their health, which was a decision to be made by the physicians.

> And do whatever is necessary that you think as a professional. Use your own opinion what you should do for me and how to make me as peaceful and comfortable. Use your own opinion. (Towsley and Hirschman 2018)

The uncertainty about that which awaited them in the process of dying was the reason why many older people felt *unable to make a decision regarding advance care planning* (Frank et al. 1998; Winland-Brown 1998; Phillips and Woodward 1999; Fried and Bradley 2003; Seymour 2003; Malpas et al. 2014; Fleming et al. 2016: Hirakawa et al. 2017; Yap et al. 2018). They understood the necessity to consider treatment options, but as they were still attached to life, they felt that any decision they made would be premature and based on ignorance about the real situation. Deciding in advance to stop treatment was as if they were sentencing themselves to death, although they might still want to live if they were in the real situation.

> How can I make well-informed decisions about treatment before an illness or injury occurs? (Winland-Brown 1998)

> If anything were to happen in the future, the signed document would become a piece of evidence. As I said before, anything can be subjected to changes. (Yap et al. 2018)

The desire to live was in fact apparent in the process of dying although older persons suffered from their disease. They *wished to be cured and to survive;* they fought their illness and told of their dreams to return to life (Benzein et al. 2001; Chochinov et al. 2002; Fried and Bradley 2003; Laakkonen et al. 2004; Ryan 2005; Nebel Pederson and Emmers-Sommer 2012; Devik et al. 2013; Coelho et al. 2016; MacArtney et al. 2016)

> I'm trying to fight the disease as best as I can, and that's why I express the feeling that perhaps I should be released and be able to go home. (MacArtney et al. 2016)

> Obviously I hope I'll get well, or at least better, you have to have hope … that's what keeps people going. It's not that I think there will be some miracle, but obviously you want to get well, the hope remains, you never know … perhaps someone will come one wonderful day and say they've found a new medicine. (Benzein et al. 2001)

When these older persons realized that their chance to be healed was minimal, they nevertheless had a *desire to prolong their lives in the process of dying*—even if it was just for a short period of time (Laakkonen et al. 2004; Devik et al. 2013; Haug et al. 2015, 2016; MacArtney et al. 2015, 2017)

> Well, I want to carry on with the chemo obviously because I want to be around for a bit longer. I don't really want to die just yet. (MacArtney et al. 2015)

For the same reason, some of the terminally ill older persons were still in favour of resuscitation:

> Yes, I do think that something should be done or at least tried. They should try to make attempts to the very end. (Laakkonen et al. 2004)

Some of these older persons choose to accept palliative care in the belief that it was a treatment with life-prolonging options (MacArtney et al. 2015). More common, however, was a rejection of palliative care because older persons perceived the *hospice as a warrant of death* (Waldrop and Meeker 2012; El-Jawahri et al. 2017; MacArtney et al. 2015, 2017)

> I feel a little bit hesitant about hospice, I guess scared is the right word. I am a bit standoffish about what I might run into. (El-Jawahri et al. 2017)

> So there's this connotation in your mind where if you're going to a palliative care doctor you think 'oh god, I'm dying!' And I know I'm dying but I'm hoping it's a little bit further away than that. (MacArtney et al. 2017)

6.5.2.2 Satisfaction of Attachment to Life

Older persons' attachment to life was of course satisfied as long as they found that they were still alive. *Getting treatment* had the same effect, since it confirmed their hope for survival.

> I mean the people in the chemo are keeping me alive and they've done a great job. (MacArtney et al. 2017)

On the long run, however, they experienced a *breakdown of their resilience* (Ryan 2005; Dees et al. 2011; Rurup et al. 2011; Waldrop and Meeker 2012; Nebel Pederson and Emmers-Sommer 2012; MacArtney et al. 2015, 2017). Mentally and physically exhausted, they were finally worn out by their disease and realized that they were losing the battle.

> I always said I wouldn't ever give up, but it is hard not to. I said I would fight it as long as I could. (Ryan 2005)

> Mentally I am completely exhausted. I can't fight it anymore. (Dees et al. 2011)

As a consequence, these older became more and more inclined to a detachment from life.

6.5.2.3 Detachment from Life

Attachment to life was more or less counterbalanced by the opposite orientation of action. With regard to advance care planning, not every older person wanted a prolongation of life. As mentioned earlier, many of them feared that excessive treatment would only prolong their pain or turn them into a brainless body. Consequently, they *preferred death instead of useless suffering* (Blackhall et al. 1999; Leichtentritt and Rettig 1999; Rosenfeld et al. 2000; Fried and Bradley 2003; Young et al. 2003; Baeke et al. 2011; Ball et al. 2014; Ko et al. 2015; Fleming et al. 2016; Lewis et al. 2019). Observing the deterioration of others confirmed them in their opinion.

> If [my doctor] told me that I'd die tomorrow unless I took this and then I'd probably live another year with being sick all the time, I'd take the die tomorrow. (Fried and Bradley 2003)

> I see… the daily deterioration of people… people going from walking to the walker to the wheelchair, and then finally over to the hospital… given my druthers at a certain point in that… I would prefer to go rather than to see that I was taking that same route… (Rosenfeld et al. 2000)

When older people actually went through the process of dying, some of them were no longer so sure about this issue. They were rather *caught between the desire to live and the desire to die* (Benzein et al. 2001; Fried and Bradley 2003; Rurup et al. 2011; Devik et al. 2013; MacArtney et al. 2015, 2017; Bollig et al. 2016; Fleming et al. 2016).

> You wonder at times whether the discomfort you have is worth it, but then you wonder, well, how much more life you're going to have and what kind of life you're going to live and whether it's going to be worthwhile. Yeah it's a very difficult decision to say, 'no, I won't have the treatment' […] But then I've seen others who have been on the intravenous [chemotherapy], how sick they get too, so I'm not sure that I'd want to go that way … No matter what you say today, you'll think quite differently tomorrow. (MacArtney et al. 2017)

However, a progression of their disease could make them *long for death to escape from suffering* (Chochinov et al. 2002; Laakkonen et al. 2004; Andersson et al. 2008; Dees et al. 2011; Waldrop and Meeker 2012; MacArtney et al. 2017). They realized that further treatment was futile, and since they were "done with the chemo" (Waldrop and Meeker 2012) they rejected it.

> It is such an aggressive form of cancer. I saw all my energy going down the drain - what I could still do last week I can't do at all now. I really enjoyed my life, but now I have just to wait and see how things go and what death will look like (Dees et al. 2011)

> Oh yes when I had that terrible pain and it got so bad. […] And then of course I had days when I thought oh God take me, take me home…take me home. I'm ready to go right now. Right now. (Chochinov et al. 2002)

Others were not exhausted by the treatment of an incurable disease like cancer, but suffered from a gradual decline or unhappy circumstances of life that eventually made them *give up* and convinced them that death was better than life (Engle et al. 1998; Benzein et al. 2001; Becker 2002; Lambert et al. 2005; Dees et al. 2011; Rurup et al. 2011; Ball et al. 2014; Cable-Williams and Wilson 2014; Fleming et al. 2016)

> Cause I don't enjoy when I ain't nothin' but sick. (Engle et al. 1998)

> I am tired of life and that has to do with my marriage, which was difficult. Not every day, but regularly and that was not so pleasant. (Dees et al. 2011)

There were also those who did not suffer from pain, but simply felt they had lived too long and *lost their desire to live* (Leichtentritt and Rettig 1999; Lambert et al. 2005; Andersson et al. 2008; Whitaker 2010; Dees et al. 2011; Bollig et al. 2016; Fleming et al. 2016)

> I wish I was dead. I gave my part to the society. I worked hard all my life, raised two daughters—did my share, now it is time for me to die. How do I know it is time? It is difficult to explain. You just have a feeling of "enough" in your body as well as in your thoughts and feelings. A feeling that you do not want any more. When I was little and we did not have enough to eat, especially during the war, I kept on thinking that I will have no eating limits as soon as the war is over, I will just eat and eat and eat … but my body puts a limit to the process. There is a point in the eating process when you can no longer eat a thing, and if you chose to put something in your mouth, even your favourite dish—you feel sick. This description is a very simplistic explanation to the same feelings I am experiencing today. (Leichtentritt and Rettig 1999)

If for one of these reasons the detachment from life became too strong, older persons expressed their *wish for assisted suicide* (Wilson 2000; Dees et al. 2011; Fleming et al. 2016; van Wijngaarden et al. 2016a, b). However, terminating one's life was not so easy, and those who wanted to kill themselves were *torn between a desire to live and a desire to commit suicide*.

> I feel like I'm holding a splits position. On the one hand, I definitely want to die. On the other hand though, there is still simply too much physical, intuitive life force. (…) So you just live on, you breathe, you eat and uh, take care of yourself. I mean, if you are really done, you would stop eating, wouldn't you? (…) But that physical body of mine tells me: "I'm hungry for a sandwich." So, I have a sandwich. (…) That's the dilemma I'm living in: you rationally want to die, but at the same time, there's that unbreakable will to live, which makes me feel I'm being pulled in two directions. (van Wijngaarden et al. 2016a).

The only solution they could imagine to escape from this dilemma was the hope of being killed by external circumstances that would save them from dying by their own efforts:

> All the time, I'm thinking: How to die? The only hope I have is that I am run over by a car. Or when I hear about an airplane accident, I think: Oh, I wish I was on that plane! (ibid.)

6.5.2.4 Satisfaction of Detachment from Life

Older people who were detached from life lost their fear of death and *were able to accept their end in a calm and serene way* (Engle et al. 1998; Leichtentritt and Rettig 1999; Rosenfeld et al. 2000; Benzein et al. 2001; Forbes 2001; Carrese et al. 2002; Chochinov et al. 2002; Munn et al. 2008; Nebel Pederson and Emmers-Sommer 2012; Ball et al. 2014; MacArtney et al. 2015, 2016, 2017; Bollig et al. 2016; Fleming et al. 2016; Coelho et al. 2016; Towsley and Hirschman 2018).

> I've resigned myself to the idea that I'll die soon … that's life … I can't do anything about it, no … I've resigned myself to it and it feels good. (Benzein et al. 2001)

> As far as death goes, well, when it comes to it, when your number's up, your number's up, that's my philosophy and I don't worry about it. (MacArtney et al. 2017)

Staying in a palliative care setting could facilitate such acceptance, since the availability of help reduced the fear of suffering from pain in the process of dying.

> How I feel here [in SPC]? It changed, it's a big change. It's very, very good here. And I am more relaxed because I know, when I really, moment come, they here with me, and could give me help. (MacArtney et al. 2015)

A detachment from life, however, did not mean that everything was senseless and in vain. Dying rather had a meaning, because in the eyes of these older persons *death was a relief* from pain and suffering and could also be a source of hope provided they believed in an afterlife (Engle et al. 1998; Becker 2002; Lambert et al. 2005; Rurup et al. 2011; Bollig et al. 2016; Tishelman et al. 2016; van Wijngaarden et al. 2016a).

> If I'm dead, I'm not going to suffer. It's like when you're having an operation and they put you under so you won't feel it when they're chopping you up … so when you die, you're not going to feel anything…. There's no pain, no suffering, there's no regrets. I'm like most people, I have my regrets, I think we all do at this stage, but when we die there's none of that. (Lambert et al. 2005)

> I've thought about it, but it don't scare me… I guess it's just … I'd leaving this world and going to a better place. (Engle et al. 1998)

However, the desire for detachment from life was not fulfilled when elderly people felt that they *were unable to die or had not died in time* (Whitaker 2010; MacArtney et al. 2017).

> I wish I would have died then [when I had the stroke], I would have been in heaven now. But I didn't die then, so I wasn't wanted then… (MacArtney et al. 2017)

Those who asked for assisted suicide were *plagued by fear of a failed attempt at suicide* that might even prolong their suffering instead of ending it.

> How can I be sure that I don't cause irreparable damage to my body or end up in a coma?' (van Wijngaarden et al. 2016a)

6.5.3 Denial of Adversities Versus Facing Adversities

Attachment to life is usually associated with a denial of the possibility to die. As Kübler-Ross (2014) said: "Man has to defend himself psychologically in many ways against this increased fear of death and increased inability to foresee and protect himself against it" (p.14), and she adds that "in our unconscious we cannot perceive our own death and do believe in our immortality" (ibid.). Such denial of death is in fact a precondition to pursue life, since a persistent idea of dying soon would paralyze one's ability to act. However, if people suffer from a malignant disease it becomes increasingly impossible to maintain such denial as they begin to feel inside themselves that something is wrong. In response they develop a desire to find out the truth and to face the adversity.

6.5.3.1 Denial of Adversities

As Kübler-Ross (2014) said, older persons *avoided to think about death* in their everyday life (Winland-Brown 1998; Carrese et al. 2002; Bollig et al. 2016; Fleming et al. 2016; Hirakawa et al. 2017; Towsley and Hirschman 2018). Death seemed to be far away and therefore it was better not to think about it.

> People think death isn't going to happen, people think they are immortal. (Winland-Brown 1998)

> I hope our current daily life remains stable forever. (Hirakawa et al. 2017)

> Well, I don't think about the final one so far, I'm still living. (Towsley and Hirschman 2018)

This attitude was also reflected in the *avoidance of advance care planning* which was observed in many older persons (Kelner 1995; Winland-Brown 1998; Fried et al. 1999; Carrese et al. 2002; Seymour 2003; Horne et al. 2006; van Leuven 2011; Gjerberg et al. 2015; Bollig et al. 2016; Lee et al. 2016; Thoresen et al. 2016; Romo et al. 2017). Some said that there had been no time and opportunity to discuss this matter with their family or physician; others admitted that they had never thought about it because there was no reason to do so, and others even rejected it or felt uncomfortable when routinely questioned about this matter when they were admitted to a nursing home (Thoresen et al. 2016).

> No, there is little talk about that (ACP) because they (the staff) are so busy. (Bollig et al. 2016)

> I don't want to think about it. I just want to live as long as I can. (Kelner 1995)

Regarding the question of whether persons with a malignant disease should be informed about it, some older persons also expressed a *desire not to know the truth* (Frank et al. 1998; Laakkonen et al. 2004; Yap et al. 2018).

> If the patient were to know their disease it would cause anguish. So I think it would be better not to inform the patient, and in that way the patient could pass away less fearfully. (Frank et al. 1998)

The same attitude was found among older persons who had been informed about their condition. In this case they preferred not to know details of their prognosis and the future course of their treatment.

> I don't want to hear if they are saying that you have this or that much time left. I don't want to know that kind of thing. Well, it will all come in good time. (Laakkonen et al. 2004)

If they wanted to be informed at all, then they just wanted to hear the truth that they desired:

> It must be that kind of truth that gives me some joy, so to say. Not information about that my life soon will be over. Clearly, it must be details that benefit me. It's not that fun to hear that I have a limited time left. I don't think that the truth should be too… well it has to be a little bit modified. (Friedrichsen et al. 2011)

According to Kübler-Ross (2014) denial is the first stage in the dying process and it often appears in an *unwillingness to believe that death is approaching* (Vig and Pearlman 2003; Laakkonen et al. 2004; Ball et al. 2014; Coelho et al. 2016; Fleming et al. 2016; MacArtney et al. 2017). At least some older persons confirmed her observations. They completely denied their diagnosis or they were attached to an unrealistic hope to be cured.

> This is a temporary situation of one or two months which will end. This situation does not worry me, every day I improve greatly and I am very positive. (Coelho et al. 2016)

> By saying: I am fine! The disease goes away quicker… (ibid.)

Others thought that they still had time although they were in the middle of their treatment:

> I've been through the radiation therapy, I've started the chemo and so far so good. And I've just come down here to see [the specialist palliative care consultant] about four weeks ago I think it was just as an initial visit, and today was just a follow-up. But currently I haven't been here at all basically, I'm just, it's in the future, it's all in the future. (MacArtney et al. 2017)

Not thinking about death and distracting oneself was another way to achieve denial (Vig and Pearlman 2003; Duggleby and Wright 2004).

> I usually block that from my mind. (Duggleby and Wright 2004)

> You hope to get by by keeping yourself busy. (ibid.)

Should death be inevitable after all, they *wanted to die without noticing it* (Wilson 2000; Vig et al. 2002; Vig and Pearlman 2004; Fleming et al. 2016). In this way, they did not only hope to avoid pain but also the awareness of dying itself.

> Oh, just going to sleep one night and not waking up. It would be a very easy, fast way to go, no drugs, no side effects, so to me that would be real easy. (Vig and Pearlman 2004)

6.5.3.2 Satisfaction of Denial of Adversities

To some extent, older persons were able to deny their dying (Fried and Bradley 2003; Devik et al. 2015; Haug et al. 2015: Haug et al. 2016). At least *temporarily they felt good* and had nothing to complain about when they received treatment.

> Don't talk to me about being sick. I just feel fine, and the side effects of chemotherapy are almost not bothering me at all. (Haug et al. 2015)

In the long run, however, such denial was impossible. This could already occur when older persons were involuntarily confronted with the issue of advance care planning and became suddenly aware of their approaching end. One daughter described her mother's *depression after a conversation about advance care planning* when she was admitted to a nursing home:

> She has lived at home until now, and her hope was to continue to stay at home as long as possible, and then all of a sudden, everything is changed, and of course, that makes you lose your strength and your optimism, and…it doesn't help (your mood) to have such a conversation right after admission to the nursing home…I can see that she has become …you become a bit depressed moving to a nursing home because it is the last stop. (Thoresen and Lillemoen 2016)

Those who suffered from a malignant disease experienced of course a *shock when they heard their diagnosis*, and the awareness that they were about to die made them desperate (Duggleby 2000; Benzein et al. 2001; Ryan 2005; Haug et al. 2016).

> I had a nervous breakdown when I was diagnosed with lung cancer. If my family hadn't been there, I don't know what I would have done. (Haug et al. 2016)

> To me, it's painful to think about that I just have a little while longer to live. (Duggleby 2000)

Fears and worries during treatment prevented subsequently their attempts of denial. They were caused by medical uncertainty and increased by the experience of symptoms that worsened their condition.

> Your body is changing gradually with this cancer, and you get different signals from your body. And that's scary because you don't know how to handle them. If you're lying there in bed and you get something—all of a sudden you get a chest pain, let's say, severe chest pain, so you wonder, is this the time? (Vig and Pearlman 2003)

Having to accept their admission to palliative care meant for some the definite destruction of their illusion to survive and gave them no chance to further deny their condition (Waldrop and Meeker 2012; MacArtney et al. 2017).

6.5.3.3 Facing Adversities

Since denial of death was in the long run not possible, older persons began sooner or later to face it. When they were still healthy, they were only theoretically confronted with death. (Winland-Brown 1998; Rosenfeld et al. 2000; Becker 2002; Ball et al. 2014; Cable-Williams and Wilson 2014; Bollig et al. 2016; Fleming et al. 2016; Yap et al. 2018). As they said, death was an inevitable and natural part of life:

> There are two things you know for sure: it is to be born and to die. (Bollig et al. 2016)

However, such theoretical knowledge did not cause undue worries since they were not yet personally affected by dying and some admitted that they were not seriously thinking about this matter:

> It is easy to say that I want to know everything about my condition while I'm in good health. However, when truly faced with an illness it is natural that one does not wish to die and would become fearful of it. (Yap et al. 2018)

Despite this normal fear of death, some older persons were *ready to talk about advance care planning* and to overcome their unease if necessary (Leichtentritt and Rettig 2000; Seymour 2003; Horne et al. 2006; Laakkonen et al. 2004; Ott 2008; Malcomson and Bisbee 2009; van Leuven 2011; Bollig et al. 2016; van Wijngaarden et al. 2016a; Yap et al. 2018).

> I have talked a bit about it (ACP) with a nurse, and I appreciate to talk about death. I don't have a problem to talk about it (death). Some people put these things aside and do not even want to think about it. (Bollig et al. 2016)

> I believe it is important to talk about the issue … Avoiding the subject will not make the feelings go away. On the contrary, they just get stronger and stronger. Not at your age, but definitely at mine. At my age, ignoring the issue just makes it worse. (Leichtentritt and Rettig 2000)

When older persons actually underwent the process of dying, some were *torn between a desire for the truth and a desire for denial*. As one of them said:

> I want to know and do not want to know (about the time left) (Friedrichsen et al. 2011)

Among those who experienced a slow but steady deterioration in their health, some *gradually gave up their denial of death* and began to make their preparations for their final stage of life:

> You know, I've denied death my whole life. I was always positive that things weren't going to change, and I just didn't think you were going to die. I built a room downstairs. I don't want to go to assisted living. I want to stay here, but eventually, I will need somebody, if I live long enough. (Romo et al. 2017)

Others, however, were less hesitant and had an *explicit desire for the truth* (Frank et al. 1998; Seymour 2003; Duggleby and Wright 2004; Ryan 2005; Friedrichsen et al. 2011; Ho et al. 2013; Gjerberg et al. 2015; Yap et al. 2018).

> If I take a turn for the worse, I want to know. Even if it's serious. (Gjerberg et al. 2015)

> The truth for me is to know what it is there for me in the future. That's most important. I've been given the knowledge that there is no return… and I have to live and do the best I can for the rest of my life …That's what they told me. There are no false expectations. (Friedrichsen et al. 2011)

In contrast to those who wanted to die without being aware of it there were others who had a *desire for a conscious death* (Leichtentritt and Rettig 2000; Vig et al. 2002; Ho et al. 2013)

> [A good death] would be one you'd be in control of, you'd know it's coming and that you could, as best you can, put things in order and then—and then die. I mean, you could say, well, die in my sleep, but I'd prefer not to die in my sleep. (Vig et al. 2002)

> Not losing my mind—that is THE thing that frightens me the most. Your mind, this is who you are, losing that is the only thing I think is worse than dying. (Leichtentritt and Rettig 2000)

6.5.3.4 Satisfaction of Facing Adversities

In some cases, older persons' desire to face death was not met. In some cultures, for example, in China or Korea, it was not considered to be appropriate to inform dying persons about their condition. When some of these persons finally discovered the truth they *felt deceived* and became angry.

> I was so angry that no one told me about my cancer, not even my doctor or my children…I have the right to know…I want to make my own care decisions and I don't want any more painful medical procedures. (Ho et al. 2013)

Others, however, accepted this cultural norm and the behaviour of their children although they were less happy about it (Frank et al. 1998). In contrast to the implicit assumption of such traditions that telling the truth would cause shock and despair, there were older persons for whom knowing the truth meant an *end to uncertainty* (Seymour 2003). This knowledge enabled them to *come to terms with their death* without rejecting life (Hermann 2001; Farber et al. 2003; Nelson-Becker 2006; Waldrop and Meeker 2012)

> Being more accepting of my situation makes me feel more comfortable with it. For a long time, I was at war with myself. (Nelson-Becker 2006)

> Keep yourself involved in your life, stay invested. I know I'm going to die and I wish it would come sooner than later, so I'm in no denial. (ibid.)

Similarly, there were residents of long-term care facilities who no longer tried to avoid the confrontation with death. They rather regarded *death as the normal end of their live in the facility* (Nebel Pederson and Emmers-Sommer 2012; Waldrop and Meeker 2012; MacArtney et al. 2015, 2017). Facing death enabled those who lived at home to *overcome their fear from palliative care*. One older man, for example, described how he experienced his first visit to the hospice where he was expected to die:

> But coming here on Tuesday was a little bit of a push because, and I had to make sure I got over that psychological thing. But in retrospect I knew I needed to do something, and thought better to do it now whilst – I'm not well, but I'm well enough to accept it. Get in and have a look around, and potentially get comfortable with the surroundings. (MacArtney et al. 2015)

In sum, older persons who were inclined to face their death had the *chance to plan their last steps*. This meant that they were able to plan their further treatment and to arrange their final affairs (Seymour 2003; Nelson-Becker 2006; Friedrichsen et al. 2011; Waldrop and Meeker 2012; MacArtney et al. 2015; El-Jawahri et al. 2017).

> It's good to know ahead of time. You don't have to decide right then and there, but it gives you time to process everything and think about what you want to do, where you want to be, and know that there are services available, that there are options (El-Jawahri et al. 2017)

> If I know that it'll (the tumour) spread like wildfire, then I can tell my children and grandchildren that now I haven't got much time left. You have to be prepared. (Friedrichsen et al. 2011)

6.5.4 Scepticism Versus Hope

In the face of their approaching death, older persons showed two opposite tendencies. On the one hand, they were sceptical regarding a positive outcome and lowered their expectations. This could help them to endure their suffering with composure, but also result in hopelessness and despair. For this reason, the dying older persons had to search for some kind of hope that allowed them to regain their inner balance. Discovering something positive in their negative condition would allow them to die with inner peace and serenity.

6.5.4.1 Scepticism

A number of older people had a sceptical attitude, which was reflected in their *atheism* (Leichtentritt and Rettig 2000; Nebel Pederson and Emmers-Sommer 2012; Haug et al. 2015, 2016; Fleming et al. 2016). Some of them said that they simply had no religious needs, whereas others openly rejected religion since they disapproved of the way how it interfered with their lives and constrained their desire for unconventionality, as we saw two sections ago.

> I'm an atheist, or an agnostic, so I've no belief in a second… in a further life. I think it will be just as it was in the thousands of years before I was born. (Fleming et al. 2016)

> I'm not a religious person anyway. I don't believe in dead spirits, I don't believe in, the only spirit we have is when we're living. I don't know how religious you are, but I don't, ya know? (Nebel Pederson and Emmers-Sommer 2012)

Scepticism did not only concern religious expectations. Dying older persons were convinced that life would not offer them much anymore, hence they *downsized their expectations* for their remaining time (Benzein et al. 2001; Hermann 2001; Carrese et al. 2002; Fried and Bradley 2003; Ryan 2005; Devik et al. 2015; MacArtney et al. 2016). They accepted their physical limitations and the ensuing loss of self-reliance and privacy, and tried to "take every day as it comes" (Benzein et al. 2001).

> When you were younger would you plan for things that would happen in the future? Yeah, I used to think 'oh, if this don't happen, that don't happen', right? Now I don't think about it no more … Whatever happens is going to happen. I don't look for it to come, you know? (Carrese et al. 2002)

6.5.4.2 Satisfaction of Scepticism

Scepticism did not necessarily result in despair. It had its positive effects on the mind of the older persons. Those who rejected religion *felt free from delusion* and lived a life that was more in agreement with their own convictions. Such feelings had sometimes been triggered by events that made them aware of their illusory beliefs. An older man, for example, remembered how a minister of his church claimed that a young woman who had died would "go to hell" because she had not been baptized, whereas a baptized alcoholic who died some time later was said to be on his way to heaven. Out of dislike for such hypocrisy he never attended church again. His rejection of established religion, however, did not result in nihilism; he rather found the freedom to search for his own conviction, which was not determined by external norms and standards:

> I believe there must be something out there, but I'm an agnostic, is what I'm trying to say. (Nelson-Becker 2006)

Those who never had been attracted to religion felt that they remained in agreement with themselves by rejecting it until the end.

> Everything but a religious ceremony in my funeral… I was never a religious person, all those religious rituals never 'talk' with me. (Leichtentritt and Rettig 2000)

Some older persons also claimed that giving up illusory hopes allowed them to *find equanimity.*

> I don't know how long I will live—maybe one more year. I have accepted it. I am not afraid of dying because I don't believe in heaven or hell. I have a fatalistic life attitude. I think I inherited my faith and the equanimity from my father, He also died of cancer. (Haug et al. 2016)

Downsizing one's expectations could have a similar effect. Some older persons who had given up the treatment of their disease and entered a hospice claimed that they had no psychological needs.

> I'm pretty well settled. My mind is not crazy yet. (Nebel Pederson and Emmers-Sommer 2012)

6.5.4.3 Hope

Giving up illusions and downsizing expectations can be seen as a one-sided mechanism of protection. Although it was helpful to become insensitive to suffering, many dying older persons also *searched for a sense of hope* that would reveal something positive in their situation and prevent them from being overwhelmed by their suffering (Benzein et al. 2001; Duggleby and Wright 2004; Nelson-Becker 2006).

> I try to keep hope as the uppermost, but I do not always manage, because there are so many factors that play a part in this, such as my mood. (Benzein et al. 2001)

> I guess if you don't have any hope, I would say you just slowly wither away. I would almost think. If you don't have any hope, then you have nothing for the future or even for the present. (Duggleby and Wright 2004)

The search for hope did not mean to deny death and dying, but not to surrender to it.

> Most of us are going to have a tough time with the rest of our lives and our direction is down that last tough road of life and it's going to continue to be tough. What you can do is you can make it tougher in your mind or you can make it easier in your mind. (Duggleby and Wright 2004)

Since hope was a matter of mind, the dying older persons *tried to think positively* and make the best out of their situation (Duggleby and Wright 2004; Ryan 2005; Franklin et al. 2006; Haug et al. 2015, 2016; Warmenhoven et al. 2016).

> I try to see something positive in each day; i.e. look at a beautiful flower outside my window or so. (Franklin et al. 2006)

> You know, some people you could put out here in the wilderness and they'd die within, you know, a couple or three days, but there's other people you'd put out there in the same wilderness and the first thing they would do is look for a way to survive… . I mean, just as we sit here and talk and stuff, I wish it could be better, but then you realize, you know, hey, wishes might come true, they might not. You just got to take what comes and go with it. I guess it is sort a like poker playin'. You play the cards that you are dealt and go from there. Try to make the best of the hand that you've got. (Ryan 2005)

One way to achieve this goal was not to be controlled by the disease and to *downsize the trouble in one's mind* (Ryan 2005; Nelson-Becker 2006)

> I know from last week to this week how much I've lost. I've accepted everything that came along and incorporated it in my living. But my illness is not who I am. 'Don't make a religion of your illness,' is my advice. (Nelson-Becker 2006)

This attitude was often complemented by a *focus on smaller goals* that could be achieved easily (Benzein et al. 2001; Chochinov et al. 2002; Duggleby and Wright 2004; Laakkonen et al. 2004; Devik et al. 2015; Haug et al. 2015; MacArtney et al. 2017).

> I would be happy if I could go home for at least one night. (Laakkonen et al. 2004)

> I've found I've set little goals each month whatever it is, even if it's just going out for a friend's birthday lunch or, I set - and the girls have come up a lot, the two of them, so I tend to set little goals for myself to keep me motivated. (MacArtney et al. 2017)

Since planning for the future made little sense, dying older persons *tried to live in the present* and prioritized their immediate needs, which was the positive complement to downsizing of expectations (Engle et al. 1998; Chochinov et al. 2002; Nelson-Becker 2006; Fleming et al. 2016; MacArtney et al. 2017).

> I know I'm going to die pretty soon, so I want to have a little fun while I can. (Engle et al. 1998)

There were also those who tried to nourish their hope by escaping temporarily into *daydreaming*:

> Sometimes I let myself imagine that I'll live until Christmas and sometimes in the night I lie and think about where to put the tree. I know it's silly but it feels good to think about myself sitting there by the tree with everyone… a lovely picture. (Benzein et al. 2001)

The last sources of hope, however, were *religious expectations* (Benzein et al. 2001; Hermann 2001; Becker 2002; Chochinov et al. 2002; Duggleby and Wright 2004; Lambert et al. 2005; Ryan 2005; Andersson et al. 2008; Venkatasalu et al. 2014; Haug et al. 2015, 2016; Ko et al. 2015; Warmenhoven et al. 2016; Towsley and Hirschman 2018).

> I would say, out of 100%, there're 95 that will call to God. They pray. So that is a natural thing. When you face death it's in born in us that we have something else in us. We know that this life is not the end of it you know. (Chochinov et al. 2002)

> One night I know … I've never prayed before, but then it came to me that I should pray to get well, with clasped hands, it was a bit scary, I've never dared to say it before, what would people think, my children would be mad. (Benzein et al. 2001)

Such expectations were associated on the one hand with a sense of trust that encouraged older persons to leave the control of their lives to a higher power (Young et al. 2003; Nelson-Becker 2006; Munn et al. 2008; Malpas et al. 2014; Fleming et al. 2016; MacArtney et al. 2017; Towsley and Hirschman 2018), and on the other hand with some feelings of guilt that urged them to find their peace with God (Engle et al. 1998; Vig and Pearlman 2003).

> Well, being a Christian, I leave it to the Lord, yeah, what he wills. (Fleming et al. 2016)

> I guess the main thing is to get my future with God straightened away. (Vig and Pearlman 2003)

The content of these expectations varied between religions. While Christians hoped for resurrection, rewards in the afterlife, or reunion with loved ones (Engle et al. 1998; Forbes 2001; Vig and Pearlman 2003; Ball et al. 2014; Haug et al. 2015; van Wijngaarden et al. 2016a), Buddhists expected to be reborn in a hopefully better life (Becker 2002; Chan and Kayser-Jones 2005). Some also had a belief without a religious frame in a higher power that granted "a special feeling of being taken care of" (Haug et al. 2015), and some of these were even the above-mentioned atheists who rejected established religions and searched for comfort in something undefined about which they said: "Do not ask me to specify what that 'thing' is" (Leichtentritt and Rettig 2000).

6.5.4.4 Satisfaction of Hope

Despite its importance, the desire for hope was not always fulfilled. Several older persons talked about their *loss of hope*, which caused a detachment from life and a wish to die (Leichtentritt and Rettig 1999; Dees et al. 2011; Rurup et al. 2011; van Wijngaarden et al. 2015, 2016a). For them, not death, but life was the source of suffering, and the process of dying was only painful because it did not end fast enough.

> To put it simply, it is insight without perspective. Never in my life have I felt any love. If there had been some warmth and love and safety, I could have grown (ibid.)

This loss of hope had several reasons. For some, their whole life was a failure and a source of suffering (Dees et al. 2011; Rurup et al. 2011), for others it was not possible to overcome losses they had experienced in their lives (Rurup et al. 2011), while yet others had lost the desire to live because of chronic diseases or simply because of their age (van Wijngaarden et al. 2015). Loss of hope, however, was not always complete when older persons detached from life, at least some of them believed in a kind of salvation in the afterlife as we saw above. But there were also some older people who had lost their faith—either due to losses they had experienced in their previous lives or due to their process of dying itself, which made them doubt their former beliefs. *Loss of faith* was painful and led to uncertainty about that what would happen after death.

> Your mind can suffer if you don't have that faith. (Duggleby 2000)

> The hardest thing for me is what's going to happen a minute after, a month after, a year after. Will I know any of this is going on or won't I? The uncertainty is the most difficult thing to deal with. (Nelson-Becker 2006)

On the other hand, older people's search for hope often led to an intrinsic satisfaction. The longing for hope created its presence. Hope was experienced as a *feeling of inner strength and assurance* (Duggleby and Wright 2004; Nebel Pederson and Emmers-Sommer 2012; Duggleby et al. 2016). It was an encouragement and optimism that came from within, but it could also be reinforced by a dialogue with other persons or by thoughts that others had expressed.

> Actually, I kept it [hope]. I think it was always there. (Duggleby and Wright 2004)

> I think when you, um, verbalize or share your hope with somebody else, it increases your hope, and makes your hope stronger and more ingrained in you. (Duggleby et al. 2016)

> And when I'm looking at poems, I'm able to look at them and feel much more optimistic (ibid.)

Those who tried to live in the present were at least sometimes able to *enjoy the moment* (Benzein et al. 2001; Hermann 2001; Chochinov et al. 2002; Duggleby and Wright 2004; Ryan 2005; Andersson et al. 2008; Rurup et al. 2011; Ho et al. 2013; Haug et al. 2015, 2016; Coelho et al. 2016; Warmenhoven et al. 2016).

> To be able to go outside for a walk is to inflate an internal joy which makes me feel alive. (Coelho et al. 2016)

> Well there's always something worth living for. I mean, you can look out the window and see flowers growing or children on the street and hear somebody laughing you know… that makes life worth living. (Chochinov et al. 2002)

Some also told how they had been able to overcome their final crisis. They found *inner peace* and reconciled with their impending death (Benzein et al. 2001; Farber et al. 2003; Ryan 2005; Andersson et al. 2008).

> I have an inner peace and I am thankful for a lot. (Andersson et al. 2008)

Inner peace implied a disappearance of their fear of death which was a sign of detachment from life. This detachment was, however, not accompanied by a loss of hope. Rather, some older persons could *accept their death as a part of life*, and therefore perceived their life as a meaningful part of a larger whole (Benzein et al. 2001; Ryan 2005; Ho et al. 2013)

> I look at those trees out there sometime, and I say, hey, you guys are gonna be here long after I'm gone. I don't know, I mean, it all comes back to the realization that to begin with you are not going to live forever… To accept the fact that you are subject to growing older and you are subject to dying… Once you accept that fact, and I guess put it in perspective, then you can live. (Ryan 2005)

Such experiences were sometimes anticipated when older persons were asked about their ideas concerning advance care planning. An older woman, for example, was convinced that she would find a deeper meaning in the last days of her life, as she had experienced when a friend of her died.

> It sounds terrible but there is some great beauty in those last days of life. A friend of mine was dying and I would visit her every day and we felt very close to each other and I will never forget those days. I remember her family coming in and relating to her and the family dynamics were very moving and meaningful. There is something about that time which is just as important as rejoicing in the birth of a baby. (Malpas et al. 2014)

However, a deeper meaning of dying was found above all in the form of *religious or spiritual consolation* that arose from the older persons' faith (Becker 2002; Chochinov et al. 2002; Farber et al. 2003; Vig and Pearlman 2003; Duggleby and Wright 2004; Ryan 2005; Nelson-Becker 2006; Andersson et al. 2008; Rurup et al. 2011; Ho et al. 2013; Ko et al. 2015; Coelho et al. 2016; Haug et al. 2016; Warmenhoven et al. 2016). After all their suffering, faith allowed them finding a happy end in their lives.

> I feel I'm going to a better place than where I am. There won't be any pain. He said man cannot even imagine the good things that He has in store for them… . I'm not afraid to die. (Ryan 2005)

> Well, I believe completely that if I die in a state of grace, I'll go to heaven. And that is a nice place to be. I'll never be sick again. And I really, firmly believe it. So it's quite a comfort. (Vig and Pearlman 2003)

6.5.5 Influencing Factors

The fulfilment of development-related action orientations depended on the personal background of the older persons, on environmental factors and, of course, on the care they received.

6.5.5.1 Personal Background

The process of dying and the way how older persons could deal with it was shaped by their *death trajectory*. There were those who suffered from a malignant disease and were still attached to their life. For them, dying was a struggle against death and losing hope until they finally gave in and were able to accept the unavoidable. But there were also those who experienced a slow but steady decline and became detached from life. For them, the process of dying was rather a struggle against life, and they either hoped that life would end soon by itself, or they desired to terminate it.

The reaction to the approaching end was also influenced by *previous experiences* of the older persons. Witnessing the death of others had of course an impact on how older persons anticipated their own process of dying. Some of them had experienced war, and among the immigrants were also those who had fled from the terror of a dictatorship where people were killed for political reasons (Becker 2002; Lambert et al. 2005). In the light of such experiences, they saw little need for any advance care planning. As a veteran said:

> I don't want nothing. I was overseas. We didn't have a chance to have CPR. (Lambert et al. 2005)

Others were influenced by how they had experienced the death of parents or friend (Malpas et al. 2014; Haug et al. 2015; Fleming et al. 2016). Sometimes it was a shock, but other times it turned out to be an experience that gave them equanimity.

> When I look back in my family, my parents. They were alive, then they were dead, but it all went off as usual. Nothing really dramatic or anything […] Why should it be any different for me? (Fleming et al. 2016)

Others gained strength from their experience of overcoming crises when they were confronted with the approaching end of their lives (Hermann 2001). Experiences with hospitals and knowledge about hospices and palliative care made older persons either accept or decline this option for the last phase of their life. Some were dreaded by the anonymous atmosphere of hospital wards and wished to die at home (Waldrop and Meeker 2014). The expected loss of independence in institutional care had the same effect (Eckemoff et al. 2018).

6.5.5.2 Environmental Factors

The individual experiences and expectations regarding death and dying depended on cultural influences. Many older persons had grown up in societies where a *cultural denial of death* was dominant (Chan and Kayser-Jones 2005; Malcomson and Bisbee 2009; Fleming et al. 2016; Lee et al. 2016; Eckemoff et al. 2018; Yap et al. 2018; Lewis et al. 2019). As a consequence they disliked to discuss about advance care planning and to think about their own death.

> I don't think Russians really discuss those matters, it's like … something in the future and you don't really talk about this … (Eckemoff et al. 2018)

> It is very difficult to get Chinese people to talk about death. They don't want to face or accept death. There is a lot of feeling that death is a bad omen, and that if somebody dies it's a bad omen. So people don't want to even consider or think about it. They just cannot accept it. (Chan and Kayser-Jones 2005)

The idea that knowing of approaching death was harmful led in some countries, such as China or Korea, to information being withheld from those who were dying.

> In Mainland China, doctors do not tell their patients, (but instead, inform their family) about them dying because this will cause more suffering to the dying patients. (Yap et al. 2018)

This culturally determined attitude was also associated with the above-mentioned expectation that family members should decide on the treatment of the dying person (Frank et al. 1998; Blackhall et al. 1999; Chan and Kayser-Jones 2005; Yap et al. 2018). Since death was not acceptable, the main concern of families in these countries was to keep the dying person alive. Cultural denial of death also affected the decisions of older persons in their process of dying. It reinforced their attachment to life and shaped their ideas about the health care system which was expected to cure diseases. Hospice care did not fit into this context, which was the reason why some older persons perceived it to be a warrant of death and consequently rejected it (Chan and Kayser-Jones 2005; Waldrop and Meeker 2012; El-Jawahri et al. 2017; MacArtney et al. 2015, 2017). Others, who had been admitted to hospice care, were mainly interested in using the service for the treatment of their physical symptoms and their expectations reflected the biomedical approach to care while they were unaware of the holistic philosophy behind these facilities (Nebel Pederson and Emmers-Sommer 2012).

However, such cultural beliefs did not completely determine the attitudes of the older persons. Some of those who said that according to their culture the truth should be withheld from a dying person nevertheless preferred to be informed about their true condition. As a result of their own deviation from tradition, some also spoke of a *cultural change regarding death and dying*.

> I think people are more and more educated these days. Unlike in the olden days, where people would make a huge deal about such things, people these days are more accepting of issues related to life and death. (Yap et al. 2018)

There are also cultures like the Philippines where *death* is not concealed, but transformed through mortuary rites into a *cultural event* of great public concern, and immigrants from such cultures were eager to return to their homeland in order to die there (Becker 2002).

6.5.5.3 Care related to Developmental Needs

The culture of any country is also reflected in its institutions. It is therefore not surprising that the cultural denial of death was translated into *institutional denial*. This was a particular characteristic of long-term care facilities. Although older persons who stayed in such a facility expected it to be the last stop in their life, there was little or no attention paid to the issue of end-of-life care. The focus was on maintaining the life of the residents, and the staff was mainly concerned about their functional and nutritional status (Forbes 2001). Nurses and aides stuck to task-oriented care, kept themselves busy with turning bedridden residents, changing their diapers, and giving them their medication, but behind this restless activity there was uneasiness about death. As one staff member said about her co-workers:

> A lot of nurses and aides, well… they've not accepted that, they are afraid of it. We're in a society where it is hard to accept death, for a lot of people. (Forbes 2001)

Not surprisingly, these nurses and caregivers were reluctant to talk about dying and end-of-life care with the residents in order to elicit their preferences.

> That would usually be with the responsible party and that's Social Services. That's not Nursing. (Towsley et al. 2015)

And a nurse who had to participate in end-of-life conversations that were routinely held at the admission of new residents said:

> I am happy that I am not the one to talk about this, I keep myself in the background. (Thoresen et al. 2016)

Because death unsettled caregivers and nurses, they assumed that this was also the case with the older persons. When a resident was about to die, they tried to conceal it from the others (Ball et al. 2014) and to remove the body in a secret way (Munn et al. 2008). As a housekeeper in an assisted living facility said:

> We don't do that because that's not going to make them feel no better about being here and knowing one of their neighbours done just passed. So we don't go out spreading that kind of word, that kind of way because we don't want to get the other residents upset. (Ball et al. 2014)

The residents reacted to this concealment of death with curiosity, but mostly not with excessive grief.

> You find that it gets over the grapevine sometimes, because the staff's not really supposed to talk about - that's another one of the rules. They're not supposed to come up here and tell them something has happened. Like if somebody dies and you've got a suspicion that something's happened, you ask them, they'll say, 'I can't talk about it.' … Well usually it gets out some kind of way because somebody can go snoop and they'll find out and then they'll tell it. (ibid).

> Well you feel sorry for a half hour and then… (ibid.)

The institutional denial of death, however, was not without its problems. Due to the avoidance of end-of-life discussions, some facilities had made bad experiences with residents dying on their way to the hospital or shortly after admission, which resulted in misunderstandings or disagreements between relatives and staff about the intensity of treatment (Thoresen et al. 2016). In response, some facilities began to introduce advance care planning at admission. However, such routinely held discussions tended to become a mere *administrative act* aimed at relieving the facility of an organizational problem and left the older persons in a state of depression since they suddenly had to realize that this was their final stop in life (ibid.). Dealing with advance care planning in such a routinized way can even be seen as another expression of institutional denial of death since it allowed the staff to avoid the direct confrontation with the emotional distress of the older persons. This attitude also led at other occasions to *inattentiveness to older persons' needs*. Kayser-Jones (2002) observed such an event where a resident said to a nurse, "I am dying", and the nurse replied in an attempt to downplay his worries, "Well, don't worry. Everybody will go to heaven". In facilities where caregivers and nurses did not care about the residents' fear of death, there was also little or no attention to their spiritual needs (Forbes 2001). Lack of attention to the feelings of older persons was also apparent in some cases of *insensitive communication* when informing them about their condition.

> He [the gastroenterologist] was about halfway a smart aleck. He didn't have no bedside manners or nothing. He just broadsided me -get out of my way, I'm running this place. I was sitting up on the table, and he said, 'You got cancer!' Well, if he had shot me right then, you couldn't have done nothing worse. I just fell to pieces, and he told me where it was, about the size of a peach seed at the end of that tube that comes down to your small intestine. (Ryan 2005)

Such incidents did not only prevent older persons from satisfying their need for denial, but also interfered with their attempt to regain hope and inner balance. Fortunately, there were also examples of *sensitive communication* from both nurses and medical doctors which had the opposite effect. Such conversations were characterized by openness, sincerity, and empathy and enabled the dying persons to face the truth while at the same time keeping some hope.

> They [Nurses] approach you and talk about cancer… a lot of people hide their emotions, they can't cope with it. All of the staff have approached it… in the manner that I would have liked to have been approached… Because of the nature of their work, you have the confidence in speaking to them, speaking about what's going to happen to you, where you're going and what's the by-product, the future, without any of the silliness. (Jack et al. 2016)

> He usually sits down and talks to you, and he takes the time to listen to what I am saying. I asked him some questions, and he said, 'Did you want to see your chart?' Which, I mean, nobody else had did that… I was free to look through anything I wanted to… I never had been able to do that. Any question I had to ask, he was gonna try to answer. He sits down with you. He tells me what I need to know. But, I mean, I want you to be truthful with me. I don't want no ifs, ands, or buts. Give me what's the facts. (Ryan 2005).

An open dealing with death was also practiced in the hospice, which had been founded for this purpose. But there were also some long-term care facilities that were not characterized by an institutional denial of death. In one of these facilities staff members had learned that death was "a part of reality" for residents, and in order to create an environment of greater openness, they held *sessions with residents to discuss death and dying* (Ball et al. 2014). The same facility *dealt with death in an open way*. Residents were informed when their roommates had passed away and if possible a memorial ceremony was held allowing everyone to bid farewell.

> So when a resident passes away, I don't try to keep it a secret. I openly tell them 'Mrs. Sandra Wiley has passed away and she has left us.' That's why I am so grateful for the families that not only have an outside burial but they allow us to do a memorial. That means so much to them [residents], so much, then the ones that may have been the next-door neighbour or the one that ate lunch with them, to give them a chance to share their relationship or their feelings about the person. It helps. It goes such a long way. (Ball et al. 2014)

Some facilities were also attentive to the individual needs of the dying persons and *allowed them to create a homelike atmosphere* by bringing in own belongings so that they could satisfy their attachment to their past (Hilário 2016; Tishelman et al.

2016). To foster hope, some nurses and caregivers tried to *give comfort* by singing or praying with the dying persons or just by talking to them and touching them.

> It's good to do it though, to talk with them nicely, sweetly, and to touch them. It helps them feel good. (Kayser-Jones 2002)

6.5.6 Behavioural and Attitudinal Reactions

The confrontation with death and dying is the ultimate crisis of human life. Due to the natural attachment to life, the first response of the older person was denial. It was apparent in the avoidance to think about advance care planning, but also in the unwillingness to believe that death was actually approaching. Since these attempts of denial were futile in the long run, older persons reacted to their own denial with a desire to know the truth, as even an unpleasant truth seemed to be preferable to uncertainty about their condition. Those who faced death in advance had the chance to plan their last steps and were to some extent prepared for the process of dying.

In view of their approaching death, many older persons still were attached to their life. Those who suffered from a malignant disease struggled against it until they were worn out by the battle and reached a point where they felt they had lost it. In reaction, they finally detached themselves from life. This process occurred in a tension between scepticism which made them downsize their expectations and hope which encouraged them to find something positive in their negative condition. Religious practices like praying, attending ceremonies, or reading religious scriptures and pamphlets were a common way to find hope in the process of dying.

> Dying with dignity means…that is facing death is, I would say, out of 100%, there're 95 that will call to God. They pray. So that is a natural thing. When you face death it's in born in us that we have something else in us. We know that this life is not the end of it you know. (Chochinov et al. 2002)

6.6 Discussion

The aim of this metasynthesis was to describe older persons' quality of life in the process of dying. Like the other metasyntheses presented in this book it has of course some limitations. One problem concerned the inclusion of appropriate studies, since many studies on the process of dying have no strict focus on older persons. They rather include any adult person undergoing this process. Since this metasynthesis was only concerned with the experience of persons above sixty years of age, studies involving younger participants had to be excluded, although they might have provided additional insights into the perspectives of older participants. However, it made little sense to discard all studies that were not restricted to older persons. Therefore, studies involving younger participants were included provided that the majority of participants were above sixty years of age and that it was discernible which statements and experiences were actually made by the older participants. Despite these requirements, it cannot be ruled out that sometimes statements have been included that rather reflect the perspectives of younger persons.

A special feature of this metasynthesis was that it was not restricted to studies on the actual process of dying, but also included studies on the hypothetical phase of advance care planning. This allowed a comparison to be made between the ideas about dying and its reality.

This comparison showed that attitudes which arose in the process of dying were already present in advance care planning. The decision for a prolongation of life corresponded to the attachment to life that could be observed in the process of dying. The rejection to prolong life in advance care planning corresponded to the decision to stop the treatment of a malignant disease. And the avoidance to think about advance care planning corresponded to the denial of approaching death. However, such similarities between the hypothetical phase of advance care planning and the actual process of dying do not allow the conclusion that one might predict attitudes as they occur in the real process based on statements made in the hypothetical phase. Such a conclusion would require long-term studies that first observe how older persons think about their death in advance and then how they react to their real dying process. No such study has been performed to date. In this context, one should also keep in mind the doubts expressed by some older persons regarding the validity of advance care planning. As they said, they could hardly foresee how they would feel in reality when the time of their dying had come. One may indeed question to what extent participants in studies about advance care planning express their true opinion. Young et al. (2003), for example, observed, that their "respondents often negotiated meaning by drawing on rigid schemas, specific mental constructs already in place: The Lord's Will, Machine Talk, Being a Burden, and Being Productive". Such standardized statements can be regarded as an expression of generally accepted opinions but not as an expression of individual considerations. However, one has to ask what participants in such studies should say, with the exception of such prefabricated opinions. Since the real experience of dying remains unknown until the process of dying begins, older persons can only refer to what is commonly said about it.

As far as the process of dying itself is concerned, the findings of this metasynthesis can be related to the different trajectories of dying that have been mentioned in the beginning. The only exception was the experience of a sudden death that cannot be investigated in qualitative research. The trajectory of malignant diseases which was described by Kübler-Ross (2014) also exists in old age. The stages she identified were also found in the investigated studies. Denial was apparent in the unwillingness to believe that death was actually approaching; bargaining could be observed in the older persons desire to prolong their lives in the process of dying; depression was a sign of a loss of hope, and acceptance was a sign of equanimity. Hope, which according to Kübler-Ross (2014) is present in every phase, was also found and could be differentiated into two aspects. On the one hand, it was an expression of the older persons' attachment to life that made them believe in a chance to be cured, on the other hand, it was the ability to find something positive in the face of inevitable death, a deeper meaning of life and suffering, which often took the form of religious expectations. Only the stage of anger was not identified—most probably because the findings investigated here were based on interviews with dying persons who were unlikely to admit their anger due to social desirability.

In contrast to the trajectory described by Kübler-Ross (2014) which is characterized by an attachment to life and a struggle against death, there was also another trajectory that seemed to be driven by a detachment from life. In this trajectory, quality of life was not compromised by impending death; rather, it had already been lost and death appeared to be a remedy to restore it. Sometimes, a chronic disease that resulted in unbearable suffering was the reason for this trajectory (Dees et al. 2011), sometimes it was just very old age and functional decline (Fleming et al. 2016) that made older persons believe that they were just a nuisance, had nothing to live for, and had lived long enough. Van Wijngaarden et al. (2015, 2016a, b) even reported about cases where older persons with no serious health problems had lost the feeling of having a purpose in life and became tired of living. Among these older persons, there was only a gradual difference between those who said they were waiting to die and those who desired assisted suicide. This difference was partly due to the fact that in some countries assisted suicide was legally permitted, whereas in others it was not.

Older persons who stayed in long-term care facilities were another group of persons who showed signs of this trajectory. Already in the previous chapter we heard about residents, who had no expectations for the future and hoped to die soon. In the light of the findings of this chapter, we should reconsider their experiences as an expression of their detachment from life. In addition to this, the character of long-term care facilities also appears in a new light. Whereas in the previous chapter these facilities were considered as a place of living where—unlike hospices—death was a short disturbance until life could return to normality, it becomes now apparent that these facilities should also be considered as places of dying. Already Gubrium (1997) described in his book "Living and Dying at Murray Manor" how residents "live with the knowledge that dying and death are imminent events for them" (p. 197). Due to the tendency of many countries to reduce costs of care, which results in a concentration of frail older persons in long-term care facilities, this experience has been reinforced. The presence of death and dying tends to become a major feature of contemporary long-term care facilities. The difference between hospices and nursing homes becomes increasingly blurred. For a growing number of residents, staying in a nursing home means more or less the same as receiving end-of-life care. For them, moving into a nursing home is not a transition from life at home to life in the facility, followed some time later by a transition from life to death. Rather, both transitions tend to merge into one. Both caregivers and residents know that those who once entered are unlikely to return to the normal life of society.

Shield (1988) who performed an ethnographic study in an American nursing home compares the situation of the residents with a state of liminality. Liminality has been described by social anthropologists as an experience of ambiguity or disorientation that occurs in the middle stage of a rite of passage used by many societies to shape the transition of their members from one stage of life to the next (e.g. the transition from youth to adulthood). Separated from the old role, and not yet installed in the new one every person is temporarily suspended in a state of "betwixt and between". According to Shield, staying in a nursing home also involves a state of liminality which is, however, not temporary as in other rites of passage that usually end with reaching the subsequent stage. The transition is rather endless, or better: there is no further stage to be reached except death. In contrast to other rites of passage, residents of nursing homes have no guidance from one stage to the other. Due to the institutional denial of death, the liminality that is also involved in the process of dying remains concealed. Officially, the nursing home is considered to be a place of life and, apart from a few facilities that cultivate an open approach to death and dying, these remain hidden realities.

Dying in nursing homes therefore is different from dying as it is experienced in traditional societies where it is still embedded in a rite of passage. Kübler-Ross (2014), for example, described how she witnessed in her youth the death of a neighbour, who died surrounded by family and friends, who came to see him for a last time and to grieve him, while he arranged his last affairs and distributed his belongings to his offspring. In some countries, the process of dying is also accompanied by religious rituals as, for example, the last rites in Roman Catholicism. In modern societies, however, such an open approach to death seems to be disappearing. Placing old and dying persons in a nursing home is just an expression of this cultural denial of death. What prevails is a belief in medical progress, which is expected to cure all diseases and eventually to abolish death. In this respect, a health system, which is exclusively focused on cure and healing, can be seen as an institutionalized form of social denial of death. In such a system, it is not surprising that Glaser and Strauss (1968) identified three main forms of the process of dying: closed awareness, where patients were kept unaware of their impending death, suspicion awareness, where patients were nagged by doubts about their true condition, and mutual pretence, where both patient and medical staff maintained the illusion of a recovery. The findings of this metasynthesis indicate that these trajectories still exist.

Of course, hospice care was introduced to change the prevailing culture and to create an open awareness for dying. To some extent, this seems to have happened as indicated by the statements of those who received this kind of care. At the same time, however, entering a hospice was associated with fear, as it was believed to be a warrant of death (Waldrop and Meeker 2012; El-Jawahri et al. 2017; MacArtney et al. 2015, 2017). One way to deal with this fear was to use its service only for the treatment of physical symptoms (Nebel Pederson and Emmers-Sommer 2012). Such expectations reflected the biomedical approach to care which was in line with the cultural denial of death. Although this denial and the belief in medical progress have their roots in the human instinct for survival, it is neither realistic nor desirable that death should be abolished. Death is a constitutive part of human life. Without an end, life would be meaningless. Since one could start over and over again, no final decision would have to be made and every action would become arbitrary.

Traditional cultures still seem to understand the meaning of human finiteness, while modern societies that worship progress are frightened by it. The extension of life that can be achieved through medical progress, however, does not provide an answer to the existential questions of life. Mere survival is indeed meaningless. This is attested not only by the statements of those who rejected a prolongation of their lives, but also by those who expressed a desire for assisted suicide.

6.7 Conclusion

The aim of this metasynthesis was to identify the relevant aspects of quality of life in the process of dying. Table 6.7 summarizes how the various orientations of action and their satisfaction are affected by this process.

Quality of life in the process of dying is not an outcome that can be produced by nursing interventions. It is not a state of well-being or happiness that can be preserved until the end of life. Medical treatment may alleviate or even eliminate physical pain until the final moment, but it cannot take away fear of death and doubts about the meaning of life. This would not even be desirable at all, because a permanent well-being and happiness would not be happiness in the real sense. The experience of happiness is never a lasting experience—in contrast to a currently flourishing ideology of happiness or well-being, which regards illness and suffering as a defect that should be eliminated as completely as possible (Zaborowski 2019). Happiness can only be experienced at a glance and it makes only sense as a moment in the ongoing process of life that finally ends with death. One may measure the degree of well-being or happiness at a particular moment of life, but such measurements make little sense because they do not take into account the context of the course of life that encompasses these moments and hence they do not capture quality of life as a whole. Quality of life does not refer to a particular moment in life but to the process of life as a whole. As such, life consists of moments of heights and depths. No such moment, however, makes sense without the preceding moments. A height is only a height in relation to a previous depth and vice versa.

Seen in this way, quality of life is the course of heights and depths. Both give life its particular profile and life without heights and depths would just be a flat and meaningless. In this sense, a depth or crisis is the loss of inner balance, while a height is the overcoming of a crisis and the re-establishment of lost inner balance. This balance can only emerge from within and it can only emerge if there are crises that are to be overcome. Crises and negative states are therefore nothing to be banished from life. They are an essential part of it, and well-being and happiness can only emerge by overcoming such crises. Of course, everybody strives for a happy end, but a happy end makes no sense without preceding drama. Any attempt to maintain a permanent state of well-being would have the opposite effect to its intention. It would create a standstill that suffocates life and thus extinguishes its quality.

Table 6.7 The process of dying and the satisfaction of orientations of action

Body-related orientations of action	
Physical activity *Satisfied* if dying persons maintain some mobility according to their capacities *Not satisfied* if dying persons suffer from loss of mobility and fatigue	*Physical rest* *Satisfied* if dying persons find some sleep *Not satisfied* if dying persons suffer from sleep disorders
Body protection and regeneration *Satisfied* if dying persons experience moments of physical comfort and are free of pain *Not satisfied* if dying persons suffer from pain or experience harm from treatment	*Negligence towards health* *Satisfied* if dying persons feel restricted by their treatment *Not satisfied* if dying persons feel to be restricted by their treatment
Food consumption *Satisfied* if dying persons can enjoy their meals *Not satisfied* if dying persons dislike the taste of food or suffer from malnutrition	*Food abstinence* *Satisfied* if dying persons can reduce food consumption according to their need *Not satisfied* if dying persons suffer from nausea
Sexual desire *Not relevant*	*Sexual abstinence* *Not relevant*
Social orientations of action	
Self-reliance *Satisfied* if dying persons maintain self-reliance *Not satisfied* if dying persons lose their self-reliance and self-care abilities	*Being cared for* *Satisfied* if dying persons feel safe and reassured since caregivers and nurses are attentive to their needs, manage their symptoms, and provide practical support *Not satisfied* if dying persons feel neglected or get inadequate help
Exerting influence on others *Satisfied* if dying persons have a feeling of control and can decide about end-of-life care *Not satisfied* if dying persons lack control due to imposed rules and routines and cannot decide about end-of-life care	*Attention to the needs of others* *Satisfied* if dying persons feel that they are no burden to their family *Not satisfied* if dying persons feel to be a burden to their family
Social adjustment *Satisfied* if dying persons can comply with social standards *Not satisfied* if dying persons feel shame for failures to meet social standards	*Unconventionality* *Satisfied* if dying persons can be spontaneous and feel unrestrained by social norms *Not satisfied* if dying persons have to suppress own needs
Closeness *Satisfied* if dying persons maintain old social contacts and can die surrounded by their loved ones *Not satisfied* if dying persons suffer from loneliness	*Distance* *Satisfied* if dying persons can enjoy their privacy *Not satisfied* if dying persons experience restricted privacy when receiving care
Identity-related orientations of action	
Work *Satisfied* if dying persons can be active according to their remaining abilities *Not satisfied* if dying persons lack activities	*Relaxation* *Satisfied* if dying persons find mental relaxation *Not satisfied* if dying persons feel mentally exhausted from their disease and failed attempts to cure it

Table 6.7 (continued)

Reflection *Satisfied* if dying persons are intellectually activated, e.g. by reminiscence *Not satisfied* if dying persons lack intellectual stimulation	*Diversion* *Satisfied* if dying persons feel entertained *Not satisfied* if dying persons lack entertainment and stimulation
Self-centredness *Satisfied* if dying persons feel relieved from duties towards others *Not satisfied* if dying persons suffer from self-neglect	*Concern for others* *Satisfied* if dying persons feel useful and can help others *Not satisfied* if dying persons feel useless and unable to prevent the sorrow of others
Self-presentation *Satisfied* if dying persons feel that they are respected and leave a positive memory *Not satisfied* if dying persons feel disrespected by others	*Self-concealment* *Satisfied* if dying persons can avoid undue attention of others *Not satisfied* if dying persons feel exposed in the eyes of others
Positive self-perception *Satisfied* if dying persons have positive memories and gain self-esteem through small achievements *Not satisfied* if dying persons lose self-esteem	*Critical self-perception* *Satisfied* if dying persons maintain a realistic self-perception *Not satisfied* if dying persons lose a realistic self-perception
Development-related orientations of action	
Attachment to the past *Satisfied* if dying persons can relive their past and die at home or in a familiar environment *Not satisfied* if dying persons do not feel at home in their place of dying	*Completing the life story* *Satisfied* if dying persons have everything achieved they wanted in their life and do not have to search for new perspectives *Not satisfied* if dying persons feel that there are open issues they cannot finish
Attachment to life *Satisfied* if dying persons get treatment to maintain their life *Not satisfied* if dying persons feel to lose their fight against death and disease	*Detachment from life* *Satisfied* if dying persons experience death as a relief or can accept in a calm and serene way *Not satisfied* if dying persons feel that they cannot die although they are tired of living
Denial of adversities *Satisfied* if dying persons feel temporarily good and can avoid worries *Not satisfied* if dying persons are shocked by their diagnosis and suffer from fear and worries about their future	*Facing adversities* *Satisfied* if dying persons are aware of and feel enabled to confront their impending death *Not satisfied* if dying persons feel deceived by others about their true condition
Hope *Satisfied* if dying persons can enjoy the moment, find inner peace and/ or religious comfort *Not satisfied* if dying persons lose their hope	*Scepticism* *Satisfied* if dying persons feel free from delusion and find equanimity in the face of death *Not satisfied* if (not mentioned)

That crises may have a meaning was reported by older people who had overcome such crises in their lives. This experience also applies to the last crisis of life, the process of dying where older persons have to face the finiteness of their existence.

A happy end to this process is not a state where the mind is anaesthetized by drugs. A good death means to die with inner peace and serenity. To die in this way requires an appropriate balance between attachment to life and detachment from life which allows the dying person to leave this life without being tired of it. This balance can only be found when dying persons gain a balance between denial and awareness of their impending death and between scepticism and hope. If care for older persons in the process of dying has a one-sided focus on their well-being, it conceals their true situation and prevents them from dealing with it. Rather, an open approach to death is required. Of course, such an approach does not mean that the process of dying should be seen as a desirable event as it compels older persons to give up their self-deception, face the truth, and think about the true meaning of their lives. How older persons want to deal with their approaching end, whether they deny it or accept it, depends solely on themselves. Nurses and caregivers may just accompany them in their process of dying by listening to them and paying attention to their needs.

However, this accompanying of the dying should not be underestimated. It gives the dying persons the opportunity to deal with their anxiety without leaving them alone. As Kübler-Ross (2014) pointed out, listening to the dying is not being inactive. If dying persons are allowed to talk about their needs, they can express their anger (which is a way of satisfying their desire for exerting influence on others), gain their lost self-esteem, and get the attention and respect from others. In other words, listening is a way to meet the respective orientations of action. At its best, it is a quiet encouragement for the dying to find the hope that they are longing for. Based on the results of this metasynthesis about the experience of dying among older persons, we would like to give the following recommendations for practice:

- Advance care planning may cause discomfort for older persons when it is routinely performed. It should therefore be initiated without urgency and with an appropriate sense for its timing. Nurses should wait for a “window of opportunity” (Seymour et al. 2010), “pick up signals” from the older person (Horne et al. 2006), and maintain advance care planning as an ongoing process (Waldrop and Meeker 2012).
- Older persons in the process of dying should receive professional treatment of symptoms by specialized hospice nurses. These hospice nurses should have a competent and comforting personality that conveys a feeling of security.
- Taking time, showing empathy and respect, and attentive listening reduce feelings of loneliness, promote feelings of dignity and self-esteem, and may help to overcome the final crisis.
- A review of life such as dignity therapy can help older persons to find meaning in their past life and thus bring it to an inner conclusion.

- Dealing with death in an open way and sessions with residents to discuss death and dying can work against a culture of denial of death and promote an open awareness of dying that allows older people to come to terms with their end.
- Provided that the dying persons are attached to traditions, rites of passage as they are found in many cultures may offer their members an orientation in the state of liminality and may guide them through this final transition.

References

Andersson M, Hallberg IR, Edberg A-K (2008) Old people receiving municipal care, their experiences of what constitutes a good life in the last phase of life: a qualitative study. Int J Nurs Stud 45:818–828

Aoun S, O'Connor M, Skett K, Deas K, Smith J (2012) Do models of care designed for terminally ill 'home alone' people improve their end-of-life experience? A patient perspective. Health Soc Care Community 20:599–606

Baeke G, Wils J-P, Broeckaert B (2011) We are (not) the master of our body: elderly Jewish women's attitudes towards euthanasia and assisted suicide. Ethn Health 16:259–278

Ball MM, Kemp CL, Hollingsworth C, Perkins MM (2014) "This is our last stop": negotiating end-of-life transitions in assisted living. J Aging Stud 30:1–13

Barclay S, Froggatt K, Crang C, Mathie E, Handley M, Iliffe S, Manthorpe J, Gage H & Goodman C (2014) Living in uncertain times. Trajectories to death in residential care homes. The British journal of general practice: the journal of the Royal College of General Practitioners 64, e576-83.

Becker G (2002) Dying away from home. Quandaries of migration for elders in two ethnic groups. J Gerontol B Psychol Sci Soc Sci 57:79–95

Bélanger E, Rodríguez C, Groleau D, Légaré F, MacDonald ME, Marchand R (2016) Patient participation in palliative care decisions: an ethnographic discourse analysis. Int J Qual Stud Health Well Being 11:32438

Benzein E, Norberg A, Saveman BI (2001) The meaning of the lived experience of hope in patients with cancer in palliative home care. Palliat Med 15:117–126

Blackhall LJ, Frank G, Murphy ST, Michel V, Palmer JM, Azen SP (1999) Ethnicity and attitudes towards life sustaining technology. Soc Sci Med 48:1779–1789

Bollig G, Gjengedal E, Rosland JH (2016) They know!-Do they? A qualitative study of residents and relatives views on advance care planning, end-of-life care, and decision-making in nursing homes. Palliat Med 30:456–470

Broeckaert B (2009) Treatment decisions in advanced disease: a conceptual framework. Indian J Palliat Care 15(1):30–36

Cable-Williams B, Wilson D (2014) Awareness of impending death for residents of long-term care facilities. Int J Older People Nursing 9:169–179

Carrese JA, Mullaney JL, Faden RR, Finucane TE (2002) Planning for death but not serious future illness: qualitative study of housebound elderly patients. BMJ 325:125

Cartwright J, Kayser-Jones J (2003) End-of-life care in assisted living facilities: perceptions of residents, families, and staffs. J Hosp Palliat Nurs 5:143–151

Chan J, Kayser-Jones J (2005) The experience of dying for Chinese nursing home residents: cultural considerations. J Gerontol Nurs 31:26–32

Chochinov HM, Hack T, McClement S, Kristjanson L, Harlos M (2002) Dignity in the terminally ill: a developing empirical model. Soc Sci Med 54:433–443

Coelho A, Parola V, Escobar-Bravo M, Apóstolo J (2016) Comfort experience in palliative care: a phenomenological study. BMC Palliat Care 15:71

Dees MK, Vernooij-Dassen MJ, Dekkers WJ, Vissers KC, van Weel C (2011) 'Unbearable suffering': a qualitative study on the perspectives of patients who request assistance in dying. J Med Ethics 37:727–734

Devik SA, Enmarker I, Wiik GB, Hellzèn O (2013) Meanings of being old, living on one's own and suffering from incurable cancer in rural Norway. Eur J Oncol Nurs 17: 781–787

Devik SA, Hellzèn O, Enmarker I (2015) Picking up the pieces. Int J Qual Stud Health Well Being 10:28382

Duggleby W (2000) Elderly hospice cancer patients' descriptions of their pain experiences. Am J Hosp Palliat Care 17:111–117

Duggleby W, Wright K (2004) Elderly palliative care cancer patients' descriptions of hope-fostering strategies. Int J Palliat Nurs 10:352–359

Duggleby W, Cooper D, Nekolaichuk C, Cottrell L, Swindle J, Barkway K (2016) The psychosocial experiences of older palliative patients while participating in a Living with Hope Program. Palliat Support Care 14:672–679

Eckemoff EH, Sudha S, Wang D (2018) End of life care for older Russian immigrants - perspectives of Russian immigrants and hospice staff. J Cross Cult Gerontol 33:229–245

El-Jawahri A, Traeger L, Shin JA, Knight H, Mirabeau-Beale K, Fishbein J, Vandusen HH, Jackson VA, Volandes AE, Temel JS (2017) Qualitative study of patients' and caregivers' perceptions and information preferences about hospice. J Palliat Med 20:759–766

Engle VF, Fox-Hill E, Graney MJ (1998) The experience of living-dying in a nursing home: self-reports of black and white older adults. J Am Geriatr Soc 46:1091–1096

Farber SJ, Egnew TR, Herman-Bertsch JL, Taylor TR, Guldin GE (2003) Issues in end-of-life care: patient, caregiver, and clinician perceptions. J Palliat Med 6:19–31

Fleming J, Farquhar M, Brayne C, Barclay S (2016) Death and the oldest old: attitudes and preferences for end-of-life care. qualitative research within a population-based cohort study. PLoS One 11:e0150686

Forbes S (2001) This is Heaven's waiting room: end of life in one nursing home. J Gerontol Nurs 27:37–45

Frank G, Blackhall LJ, Michel V, Murphy ST, Azen SP, Park K (1998) A discourse of relationships in bioethics. Patient autonomy and end-of-life decision making among elderly Korean Americans. Med Anthropol Q 12:403–423

Franklin LL, Ternestedt BM, Nordenfelt L (2006) Views on dignity of elderly nursing home residents. Nurs Ethics 13:130–146

Fried TR, Bradley EH (2003) What matters to seriously ill older persons making end-of-life treatment decisions? A qualitative study. J Palliat Med 6:237–244

Fried TR, van Doorn C, O'Leary JR, Tinetti ME, Drickamer MA (1999) Older persons' preferences for site of terminal care. Ann Intern Med 131:109–112

Friedrichsen M, Lindholm A, Milberg A (2011) Experiences of truth disclosure in terminally ill cancer patients in palliative home care. Palliat Support Care 9:173–180

Froggatt KA, Wilson D, Justice C, MacAdam M, Leibovici K, Kinch J, Thomas R, Choi J (2006) End-of-life care in long-term care settings for older people: a literature review. Int J Older People Nursing 1:45–50

Gjerberg E, Lillemoen L, Førde R, Pedersen R (2015) End-of-life care communications and shared decision-making in Norwegian nursing homes--experiences and perspectives of patients and relatives. BMC Geriatr 15:103

Glaser BG, Strauss AL (1968) Time for dying. Aldine, New York

Gott M, Seymour J, Bellamy G, Clark D, Ahmedzai S (2004) Older people's views about home as a place of care at the end of life. Palliat Med 18:460–467

Gubrium JF (1997) Living and dying at Murray Manor. University Press of Virginia, Charlottesville

Hall S, Goddard C, Speck P, Higginson IJ (2013) It makes me feel that I'm still relevant: a qualitative study of the views of nursing home residents on dignity therapy and taking part in a phase II randomised controlled trial of a palliative care psychotherapy. Palliat Med 27:358–366

Hanratty B, Holmes L, Lowson E, Grande G, Addington-Hall J, Payne S, Seymour J (2012) Older adults' experiences of transitions between care settings at the end of life in England: a qualitative interview study. J Pain Symptom Manag 44:74–83

Haug SHK, Danbolt LJ, Kvigne K, Demarinis V (2015) How older people with incurable cancer experience daily living: a qualitative study from Norway. Palliat Support Care 13:1037–1048

Haug SHK, Danbolt LJ, Kvigne K, Demarinis V (2016) Older people with incurable cancer: existential meaning-making from a life-span perspective. Palliat Support Care 14:20–32

Hermann CP (2001) Spiritual needs of dying patients: a qualitative study. Oncol Nurs Forum 28:67–72

Hilário AP (2016) In-patient hospice: a qualitative study with Portuguese patients, family and staff. Death Stud 40:290–297

Hirakawa Y, Chiang C, Hilawe EH, Aoyama A (2017) Content of advance care planning among Japanese elderly people living at home: a qualitative study. Arch Gerontol Geriatr 70:162–168

Ho AHY, Chan CLW, Leung PPY, Chochinov HM, Neimeyer RA, Pang SMC, Tse DMW (2013) Living and dying with dignity in Chinese society: perspectives of older palliative care patients in Hong Kong. Age Ageing 42:455–461

Horne G, Seymour J, Shepherd K (2006) Advance care planning for patients with inoperable lung cancer. Int J Palliat Nurs 12:172–178

Hospice Foundation of America (2018) Retrieved March 20, 2019 from https://hospicefoundation.org/Hospice-Care/Hospice-Services

Hospice UK (2019) What is hospice care? Retrieved March 20, 2019 from https://www.hospiceuk.org/about-hospice-care/what-is-hospice-care

Jack BA, Mitchell TK, Cope LC & O'Brien MR (2016) Supporting older people with cancer and life-limiting conditions dying at home. A qualitative study of patient and family caregiver experiences of Hospice at Home care. Journal of advanced nursing 72, 2162–2172.

Jarrett NJ, Payne SA, Wiles RA (1999) Terminally ill patients' and lay-carers' perceptions and experiences of community-based services. J Adv Nurs 29:476–483

Kayser-Jones J (2002) The experience of dying: an ethnographic nursing home study. The Gerontologist 42(3):11–19

Kayser-Jones J, Schell E, Lyons W, Kris AE, Chan J, Beard RL (2003) Factors that influence end-of-life care in nursing homes: the physical environment, inadequate staffing, and lack of supervision. The Gerontologist 43:76–84

Kelner M (1995) Activists and delegators: elderly patients' preferences about control at the end of life. Soc Sci Med 41:537–545

Ko E, Kwak J, Nelson-Becker H (2015) What constitutes a good and bad death?: perspectives of homeless older adults. Death Stud 39:422–432

Krau SD (2016) The difference between palliative care and end of life care. more than semantics. Nurs Clin North Am 51:ix–ix

Kübler-Ross E (2014) On death and dying. Scribner, New York

Laakkonen ML, Pitkala KH, Strandberg TE (2004) Terminally ill, elderly patient's experiences, attitudes, and needs: a qualitative study. Omega 49:117–129

Lambert HC, McColl MA, Gilbert J, Wong J, Murray G, Shortt SED (2005) Factors affecting long-term-care residents' decision-making processes as they formulate advance directives. The Gerontologist 45:626–633

Lee H-TS, Cheng S-C, Dai Y-T, Chang M, Hu W-Y (2016) Cultural perspectives of older nursing home residents regarding signing their own DNR directives in Eastern Taiwan: a qualitative pilot study. BMC Palliat Care 15:45

Leichtentritt RD, Rettig KD (1999) Meanings and attitudes toward end-of-life preferences in Israel. Death Stud 23:323–358

Leichtentritt RD, Rettig KD (2000) The good death: reaching an inductive understanding. Omega 41:221–248

Lewis ET, Harrison R, Hanly L, Psirides A, Zammit A, McFarland K, Dawson A, Hillman K, Barr M, Cardona M (2019) End-of-life priorities of older adults with terminal illness and caregivers: a qualitative consultation. Health Expect 22:405–414. https://doi.org/10.1111/hex.12860

MacArtney JI, Broom A, Kirby E, Good P, Wootton J, Yates PM, Adams J (2015) On resilience and acceptance in the transition to palliative care at the end of life. Health 19:263–279

MacArtney JI, Broom A, Kirby E, Good P, Wootton J, Adams J (2016) Locating care at the end of life: burden, vulnerability, and the practical accomplishment of dying. Sociol Health Illn 38:479–492

MacArtney JI, Broom A, Kirby E, Good P, Wootton J (2017) The liminal and the parallax. living and dying at the end of life. Qual Health Res 27:623–633

Malcomson H, Bisbee S (2009) Perspectives of healthy elders on advance care planning. J Am Acad Nurse Pract 21:18–23

Malpas PJ, Wilson MKR, Rae N, Johnson M (2014) Why do older people oppose physician-assisted dying? A qualitative study. Palliat Med 28:353–359

Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med, 6 (7), e1000097

Mulqueen K, Coffey A (2017) Preferences of residents with dementia for end of life care. Nurs Older People 29:26–30

Munn JC, Dobbs D, Meier A, Williams CS, Biola H, Zimmerman S (2008) The end-of-life experience in long-term care: five themes identified from focus groups with residents, family members, and staff. The Gerontologist 48:485–494

Nebel Pederson S, Emmers-Sommer TM (2012) I'm not trying to be cured, so there's not much he can do for me: hospice patients' constructions of hospice's holistic care approach in a biomedical culture. Death Stud 36:419–446

Nelson-Becker HB (2006) Voices of resilience: older adults in hospice care. J Soc Work End Life Palliat Care 2:87–106

Ott BB (2008) Views of African American Nursing Home residents about living wills. Geriatr Nurs 29:117–124

Phillips K, Woodward V (1999) The decision to resuscitate: older people's views. J Clin Nurs 8:753–761

Richardson J (2002) Health promotion in palliative care: the patients' perception of therapeutic interaction with the palliative nurse in the primary care setting. J Adv Nurs 40:432–440

Rietjens JAC, Sudore RL, Connolly M, van Delden JJ, Drickamer MA, Droger M, van der Heide A, Heyland DK, Houttekier D, Janssen DJA, Orsi L, Payne S, Seymour J, Jox RJ, Korfage IJ, European Association for Palliative Care (2017) Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. Lancet Oncol 18(9):e543–e551

Romo RD, Allison TA, Smith AK, Wallhagen MI (2017) Sense of control in end-of-life decision-making. J Am Geriatr Soc 65:e70–e75

Rosenfeld KE, Wenger NS, Kagawa-Singer M (2000) End-of-life decision making: a qualitative study of elderly individuals. J Gen Intern Med 15:620–625

Rurup ML, Pasman HRW, Goedhart J, Deeg DJH, Kerkhof AJFM, Onwuteaka-Philipsen BD (2011) Understanding why older people develop a wish to die: a qualitative interview study. Crisis 32:204–216

Ryan PY (2005) Approaching death: a phenomenologic study of five older adults with advanced cancer. Oncol Nurs Forum 32:1101–1108

Seymour J (2003) Technology and "natural death": a study of older people. Zeitschrift fur Gerontologie und Geriatrie 36:339–346

Seymour J, Almack K, Kennedy S (2010) Implementing advance care planning: a qualitative study of community nurses' views and experiences. BMC Palliat Care 9(1):4. Retrieved from http://www.biomedcentral.com/1472-684X/9/4

Shield RR (1988) Uneasy endings. daily life in an American nursing home. Cornell University Press, Ithaca

Skolnick AA (1998) MediCaring: project to demonstrate, evaluate innovative end-of life program for chronically ill. JAMA 279:511–1512

Steinhauser K, Christakis N, Clipp E, McNeilly M, McIntyre L, Tulsky J (2000) Factors considered important at the end of life by patients, family, physicians, and other care providers. JAMA 284:2476–2482

Thoresen L, Lillemoen L (2016) “I just think that we should be informed” a qualitative study of family involvement in advance care planning in nursing homes. BMC Med Ethics 17:72

Thoresen L, Ahlzén R, Solbrække KN (2016) Advance Care Planning in Norwegian nursing homes-who is it for? J Aging Stud 38:16–26

Tishelman C, Lindqvist O, Hajdarevic S, Rasmussen BH, Goliath I (2016) Beyond the visual and verbal: using participant-produced photographs in research on the surroundings for care at the end-of-life. Soc Sci Med 168:120–129

Todd A, Holmes H, Pearson S, Hughes C, Andrew I, Baker L, Husband A (2016) ‘I don’t think I’d be frightened if the statins went’: a phenomenological qualitative study exploring medicines use in palliative care patients, carers and healthcare professionals. BMC Palliat Care 15:13

Towsley GL, Hirschman KB (2018) Talking about end-of-life care: perspectives of nursing home residents. Geriatr Nurs 39:72–76

Towsley GL, Hirschman KB, Madden C (2015) Conversations about end of life: perspectives of nursing home residents, family, and staff. J Palliat Med 18:421–428

van Leuven K (2011) Advance care planning in healthy older adults. Calif J Health Promot 9: 6–14

van Wijngaarden E, Leget C, Goossensen A (2015) Ready to give up on life: the lived experience of elderly people who feel life is completed and no longer worth living. Soc Sci Med 138:257–264

van Wijngaarden E, Leget C, Goossensen A (2016a) Caught between intending and doing: older people ideating on a self-chosen death. BMJ Open 6:e009895

van Wijngaarden E, Leget C, Goossensen A (2016b) Till death do us part: the lived experience of an elderly couple who chose to end their lives by spousal self-euthanasia. The Gerontologist 56:1062–1071

Venkatasalu MR, Seymour JE, Arthur A (2014) Dying at home: a qualitative study of the perspectives of older South Asians living in the United Kingdom. Palliat Med 28:264–272

Vig EK, Pearlman RA (2003) Quality of life while dying: a qualitative study of terminally ill older men. J Am Geriatr Soc 51:1595–1601

Vig EK, Pearlman RA (2004) Good and bad dying from the perspective of terminally ill men. Arch Intern Med 164:977–981

Vig EK, Davenport NA, Pearlman RA (2002) Good deaths, bad deaths, and preferences for the end of life: a qualitative study of geriatric outpatients. J Am Geriatr Soc 50:1541–1548

Waldrop DP, Meeker MA (2012) Hospice decision making: diagnosis makes a difference. The Gerontologist 52:686–697

Waldrop DP, Meeker MA (2014) Final decisions: how hospice enrollment prompts meaningful choices about life closure. Palliat Support Care 12:211–221

Warmenhoven F, Lucassen P, Vermandere M, Aertgeerts B, van Weel C, Vissers K, Prins J (2016) ‘Life is still worth living’: a pilot exploration of self-reported resources of palliative care patients. BMC Fam Pract 17:52

Whitaker A (2010) The body as existential midpoint—the aging and dying body of nursing home residents. J Aging Stud 24:96–104

WHO (2014) WHO definition of palliative care. Retrieved March 20, 2019 from http://www.who.int/cancer/palliative/definition/en/

Wilson DM (2000) End-of-life care preferences of Canadian senior citizens with caregiving experience. J Adv Nurs 31:1416–1421

Winland-Brown JE (1998) Death, denial, and defeat: older patients and advance directives. Adv Pract Nurs Q 4:36–40

Yap SS, Chen K, Detering KM, Fraser SA (2018) Exploring the knowledge, attitudes and needs of advance care planning in older Chinese Australians. J Clin Nurs 27:3298–3306

Young AJ, Ofori-Boateng T, Rodriguez KL, Plowman JL (2003) Meaning and agency in discussing end-of-life care: a study of elderly veterans’ values and interpretations. Qual Health Res 13:1039–1062

Zaborowski H (2019) Die Würde des Menschen, die Fragilität des Glücks und die Sorge für den Anderen. In: Proft I, Zaborowski H (eds) Gesundheit – Das höchste Gut? Herder, Freiburg

Person-Centred Care and Quality of Life

7

Throughout this book we tried to understand the meaning of quality of life for older persons. We investigated their experiences of living independently at home, of health promotion and disease prevention, of staying in a long-term care facility, and of undergoing the process of dying. This investigation was not an end in itself. We did not try to understand the perspective of older persons just for the sake of knowing it. We were rather concerned about the question: What do the experience of older persons and their understanding of quality of life mean to us as care providers who work in one of the settings investigated here? What do they have to tell us about our work with them? The final chapter of this book will look back at the previous investigations. It will shortly summarize the meaning of quality of life as understood by the older persons in order to outline how caregivers and nurses may respond to their needs. Since this is only possible within the framework of the care relationship, this relationship needs a closer examination. On this basis, we can finally describe the principles of a person-centred care.

7.1 Quality of Life as a Process of Balance

At the beginning of this book we encountered a variety of ideas about old age. As we saw, growing old became to be perceived as something problematic in modern Western societies—despite or may be even due to their success in increasing the average duration of human life. According to Jean Améry (1994), old age was a deplorable process of mental and physical deterioration accompanied by social exclusion that resulted in the loss of a meaningful life. With this description of old age he anticipated the perspective of those older persons who nowadays express a desire for assisted suicide. In fact, in 1974 Jean Améry committed suicide with an overdose of sleeping pills—a few years after he had published his book “On Aging”.

Although Améry may be considered an extreme case, the emergence of gerontology suggests that modern societies began to perceive old age as a problem that required a scientific solution. Gerontologists made several suggestions on how to

T. Boggatz, *Quality of Life and Person-Centered Care for Older People*,
https://doi.org/10.1007/978-3-030-29990-3_7

achieve a positive ageing. On the one hand, there were the proponents of active ageing (Havighurst 1961; Rowe and Kahn 1987). According to them, older persons should remain active, promote their fitness, engage in social activities, and develop new interests as this would not only ensure their social participation but also prevent age-related diseases or at least reduce the life span of suffering from frailty. Programs for health promotion or disease prevention that are offered nowadays to older persons subscribe to this idea.

However, as we saw in Chap. 3, there were many older persons who were less inclined to comply with recommendations of health promotion programs if these had a narrow focus on physical fitness and functional improvement. Out of fear for injuries and due to their reduced physical strength they were rather inclined to physical rest and some of them also tended to withdraw from social activities. These older persons seemed to be more in line with disengagement theory (Cumming and Henry 1961), which suggests that the acceptance of losses and functional decline would increase well-being and satisfaction with life since older persons do not have to struggle in vain to perform roles they are no longer able to perform. Opponents of this idea, however, argued that such an attitude would just accelerate physical decline and reduce in this way their well-being.

As for the older persons themselves, they were mainly not inclined towards either point of view. The interviews with them rather conveyed the idea of a balance between these opposing orientations for action. Thus, a one-sided orientation to either activity or disengagement did not meet their idea of positive ageing. Furthermore, there were those who were more concerned about the satisfaction of social, identity, and development related orientations of action that were beyond the scope of health-related programs, but which were nevertheless regarded by these older persons as contributing to their health. Health had for them a broader meaning, and included the idea to find an inner balance by compensating lost abilities with the satisfaction of orientations of action at a higher level.

In sum, one might argue that despite the existence of one-sided orientations among older persons their general idea of positive ageing was to find an individual balance that would allow people to live in harmony with themselves, with the world, and with each other. This idea seems to be in line with the philosophy of Laozi we already mentioned in the beginning of this book, but also with the doctrine of the golden mean as it was described by Aristotle (1999) in the Nicomachean Ethics, where he declares that eudaimonia—the Greek term for happiness—results from a balance between two extremes, both of which would be a vice if followed without regard to the other.

Finding an inner balance, however, seems to require self-reliance. When Laozi left his homeland (which was a metaphor for his transition from life to death) he did so independently. Such a process of ageing and dying, however, does not seem to be realistic, and modern scholars assert in fact that Laozi's life belongs to the realm of legends. Undeniably, older persons suffer from diseases and functional decline that make them care dependent and eventually culminate in the process of dying. Under such conditions, finding an inner balance based on self-reliance would be an idealistic idea of old age, while its reality rather seems to look like the description given by Jean Améry (1994). However, this criticism fails to recognize that quality of life is not a state of well-being or happiness that can be preserved until the end of life. It does not mean that life will be permanently free from suffering. Suffering is a part of life, and although nobody wants to suffer, it would be unrealistic to believe, that suffering could be completely avoided. Quality of life in its true sense can therefore only be achieved if people overcome their suffering. Quality of life in the process of dying does not mean to anaesthetize the mind with drugs in order to avoid the awareness of impending death, but to accept the finiteness of life and to die with inner peace and serenity. In the same way, quality of life while receiving care does not mean to live in a permanent state of self-reliance, but to accept one's limitations and to find an appropriate balance between becoming dependent on others in order to receive their care and maintaining independence. In both cases, quality of life is not a state free of adversity, but the result of a process that also includes negative experiences. The role that caregivers and nurses play in this process depends on the one hand on the inner balance that older persons can find in their relationship to them, and on the other hand on the balance that caregivers and nurses find in their relationship to the older persons. For reasons of brevity, we will refer in the following to both nurses and caregivers as caregivers.

7.2 The Care Relationship

To understand the relationship between care recipients and caregivers and to outline the principles of person-centred care we shall have at first a look on older persons' attitudes towards their caregivers which determine how they accept their care. Next, we have to consider caregivers' attitudes towards the older persons which determine how they provide care. The attitudes of caregivers and care recipients mutually influence each other. They can unbalance each other or bring each other into balance. Person-centred care can only develop out of the interplay of these attitudes. However, this interplay does not occur in an empty space, but is shaped by an institutional framework that can restrict or promote its development.

7.2.1 Care Recipients' Attitudes Towards Care

Older persons have different attitudes towards caregivers and their care. Since care is a social relationship, these attitudes can be understood with the help of their social orientations of action. Figure 7.1 shows the different attitudes within the framework of these orientations. Some of these attitudes were already identified by Backman and Hentinen (1999), who, to the best of author's knowledge, were the first who attempted to establish a typology of care recipients.

Some older persons had a strong inclination to exert influence on their care. Provided they had sufficient financial resources, their attitude was characterized by a *critical consumption* of care (Bowers et al. 2001; Iwasiw et al. 2003; Ball et al. 2004b, 2009; Dobbs 2004; Boggatz et al. 2009; Williams and Warren 2009;

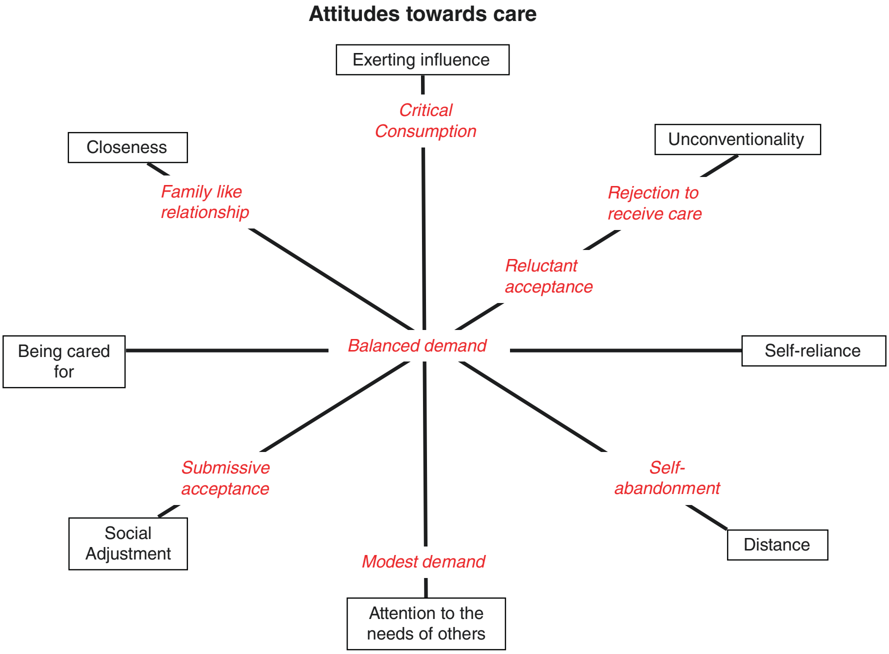

Fig. 7.1 Older persons' attitudes towards care (from: Boggatz (2019). Betreutes Wohnen. Wien: Springer)

Oosterveld-Vlug et al. 2013). They were rather demanding and ready to complain if their expectations were not met.

> When I'm paying so much I should have more to say. I'm paying good money to stay here, I should have better service. I pay $3000 a month and I can't even get a glass of water when I want it. (Bowers et al. 2001)

Caregivers felt treated like servants by these older persons or as one of them put it: "They are like, 'Get the trash and go'" (Ball et al. 2009). Other older persons were less demanding, but longed for closeness to others. They had a desire to be cared for and tried to influence the caregivers on whom they depended by establishing a *family like relationship* (Bowers et al. 2001; Josat 2005; Bland 2007; Bergland and Kirkevold 2006; Coughlan and Ward 2007; Westin and Danielson 2007; Harmer and Orrell 2008; Hauge and Kristin 2008; Cooney 2011; Nakrem et al. 2011, 2013; Chang 2013; Bollig et al. 2016a; Lung and Liu 2016; Walker and Paliadelis 2016). These older persons were longing for empathy and were willing to reciprocate with the same warmth and kindness they hoped to receive.

> I treat the nursing assistants like my friends, which means that we share what has happened here and comfort each other. (Lung and Liu 2016)

Another type of older persons was more inclined to social adjustment. They were eager to fit in to the rules and routines of the facility, did not want to make any trouble, and showed a *submissive acceptance of care* (Iwasiw et al. 1996, 2003; Chang 2013; Nakrem et al. 2013).

> Just try to work out the system and not go against it because the system is good and it's proven that it's good … just go along with it, otherwise you're going to run into a lot of problems caused by you. (Iwasiw et al. 2003)

Backman and Hentinen (1999) labelled this attitude that consists of an uncritical observance of instructions and routine performance of daily tasks as formally guided self-care.

In contrast to those who were demanding, other older persons were more attentive to the needs of their caregivers. Out of fear to become a burden for them they withheld complaints, excused a lack of care with their heavy workload, and showed only a *modest demand* for support (Iwasiw et al. 1996, 2003; Bowers et al. 2001; Chuang and Abbey 2009; Nakrem et al. 2011, 2013; Behr et al. 2013). As one of them said regarding her caregiver:

> It doesn't matter so much … I'll get along … She's so sweet and tries so hard… and I wouldn't want to hurt her feelings. (Bowers et al. 2001)

Some older persons, however, did not restrain their demands out of a fear to become a burden. They rather had downsized their expectations to such an extent that they wanted neither closeness nor care because they had *abandoned themselves*. They had detached themselves from life and all they longed for was to die soon (Lambert et al. 2005; Andersson et al. 2008; Tsai and Tsai 2008; Whitaker 2010; Dees et al. 2011; Bollig et al. 2016b; Fleming et al. 2016). Backman and Hentinen (1999) labelled this attitude as abandoned self-care.

However, there were also those who wanted to be self-reliant and live a life without restriction by social norms. Since staying in a nursing home required an adjustment to such norms, some of them completely *rejected to receive care* in such a place (Boggatz et al. 2009). Others were more realistic and felt that their functional limitations might force them to get some help. And there were also those who had been admitted to a long-term care facility because they had lost their self-care abilities. All these older persons showed a *reluctant acceptance* of care (Boggatz et al. 2009; Shaw et al. 2016; Boggatz 2019). As one of them explained their situation:

> I fiercely want to keep my independence anyway. But I feel worried about that, if I am going to deteriorate anymore and I do need some help, erm, coming to terms with having what feels a little bit invasive if that makes sense? (Shaw et al. 2016)

The attitude of persons who aimed to maintain their independence and denied the prospect of growing old was labelled by Backman and Hentinen (1999) as independent self-care. Finally, however, there were also those who were characterized by a *balanced demand* for care. They tried to be independent, but asked for care when they needed it. They exerted some influence on their care without demanding too much, as they also paid attention to the needs of caregivers. They established a positive relationship with them without giving up their distance. Backman and Hentinen (1999) labelled this attitude as responsible self-care. Such a balance may not always be achieved and it can be disrupted easily by external circumstances such as a loss of abilities or a restrictive care. It is, however, not just an ideal, since it can be attained at least temporarily and to a certain extent.

7.2.2 Caregivers' Attitudes Towards Older Persons

Caregivers had also different attitudes towards care. In a similar way as for the care recipients, these attitudes can be displayed as positions within the framework of opposing orientations of action. Figure 7.2 shows these attitudes towards care.

Some caregivers were inclined to dominance and tried to *control* the older persons (Sidenvall 1999; Koch-Straube 2003; Dobbs 2004; Hellström and Sarvimäki 2016; Kuhn 2008; Williams and Warren 2009; Oakes and Sheehan 2012; Tuominen et al. 2016). They were not really concerned about them, they just imposed rules and

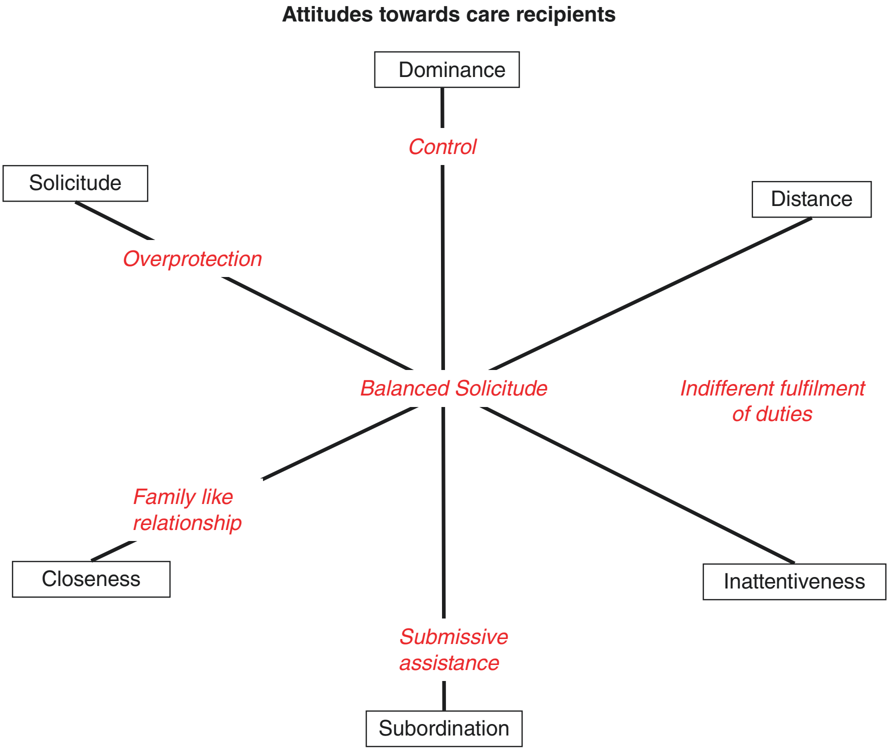

Fig. 7.2 Caregivers' attitude towards care recipients (from: Boggatz (2019). Betreutes Wohnen. Wien: Springer)

routines and expected everybody to observe them to make their work easier. If older persons were not willing to comply, they tried to educate them and in assisted living facilities they threatened to send them to a nursing home in order to make them obedient. As a certified nursing assistant admitted:

> The way you can sometimes get them to do some more things for themselves is tell them that they may have to go to the nursing… That's how we get some of them motivated. (Williams and Warren 2009)

Such behaviour produced subordination and feelings of powerlessness among the older persons but it could also result into conflicts with those who were likewise inclined to exert control. With declining health, however, these older persons were likely to lose the power struggle and become as submissive as the other residents. Dominance in the form of strict control tended towards a distanced relationship with the care recipients. However, it could also be accompanied by a tendency to solicitude. In this case it manifested itself as *overprotection* (Koch-Straube 2003; Andersson et al. 2008; Bowers et al. 2009). Out of fear that something might happen to the residents, these caregivers tried to protect them from any risk and gave them more care than they needed. Overprotection could give older persons a feeling of being cared for but at the same time it was incapacitating and promoted a loss of self-reliance.

Other caregivers were less dominant. Their solicitude was rather associated with an inclination to closeness and they liked to establish *family like relationships* with the care recipients (Murphy 2007; Ball et al. 2009; Oakes and Sheehan 2012; Adra et al. 2015; Figueredo-Borda and Zabalegui-Yárnoz 2015; Canham et al. 2016; Lung and Liu 2016). This attitude corresponded well to the attitude of like-minded older persons. Some of these caregivers talked frankly about their love for the older persons and suffered from grieve if one of them died:

> I feel like if you love older people and love working with them, I think that is love and I think you will do what you think is best for that person. That is me. All the people know that. […] We are trying to have a good time. I love my work and I love this job. Not only this job, but I take it farther, because if I see someone who needs my help I will help them. That is just me. (Ball et al. 2009)

In contrast to the tendency towards dominance, there was also a tendency towards subordination among caregivers. This attitude can be characterized as a *submissive assistance* (Murphy 2007; Ball et al. 2009; Williams and Warren 2009; Figueredo-Borda and Zabalegui-Yárnoz 2015). Caregivers with this attitude perceived themselves in a subordinated position and tried to comply with the older persons' wishes:

> I say that if they are ok, you are ok. We have to look after them so that everything's ok and we are ok, do our work well, we depend on them. It's our job.
> (Figueredo-Borda and Zabalegui-Yárnoz 2015)

Some of the Afro-American caregivers who worked in assisted living facilities did not even resist to racist insults they experienced from older persons of the white middle class:

> You have to learn to live with it….you just keep quiet and pretend that you didn't hear what they say. (Williams and Warren 2009)

This attitude suited of course older persons who had a tendency to exert control. Among caregivers, however, it could result in exhaustion to which they finally reacted with an inner distance from their work. The resulting attitude can be characterized as an *indifferent fulfilment of duties*, which involved a distanced relationship with care recipients and inattentiveness to their needs (Bowers et al. 2001; Nakrem et al. 2013; Koskenniemi et al. 2015). Occasionally, this attitude was also apparent in a dismissal of requests from the older persons, which was made with reference to the promotion of their self-reliance (Oakes and Sheehan 2012). Encouraging self-reliance was, however, not always a sign of indifference. It could also be an aspect of a *balanced solicitude* that paid attention to the needs of the older persons while trying at the same time to stimulate their resources (Oakes and Sheehan 2012; Koskenniemi et al. 2015; Naess et al. 2016). In this attitude, the opposing orientations of action of the caregivers were in equilibrium. Caregivers provided support without subordination, exerted influenced on the care recipients without controlling them, and established a close relationship without giving up their distance. At least temporarily, some caregivers were able to achieve this attitude. Whether this happened or not depended, of course, on the attitude of the care recipients they were dealing with. In the care relationship, both sides adapt to each other by searching their inner balance in the relationship to the other person.

7.2.3 The Care Relationship Within the Institutional Framework

The relationship between caregivers and care recipients does not unfold in an empty space. It is rather shaped by an institutional framework. This framework is determined on the one hand by the characteristics that both sides bring to their encounter and on the other hand by the economic and organizational conditions of the facility. The care relationship and its influencing factors within the institutional framework are shown in Fig. 7.3.

On the side of the older persons, three characteristics were of importance. Their remaining *self-care abilities* determined the range of their independence and therefore their need to receive care and to engage in a care relationship. Their *socio-economic status* was the source of their purchasing power, which was also reflected in the demands they place on caregivers. In addition, the *influence of family members* was important, as they were often the ones who arranged for admission to a care facility and who spoke on behalf of the residents with the staff. On the side of the caregivers, at first their *professional competence* was of importance. Caregivers who worked in assisted living facilities had often no professional qualification. They came from the lower classes, had previously worked in other low-paid jobs, and received only on-the-job training to perform their duties, as a longer period of formal training was not required by law for staff in assisted living (Ball et al. 2009; Kuhn 2008; Williams and Warren 2009; Jordan 2010). A similar level of

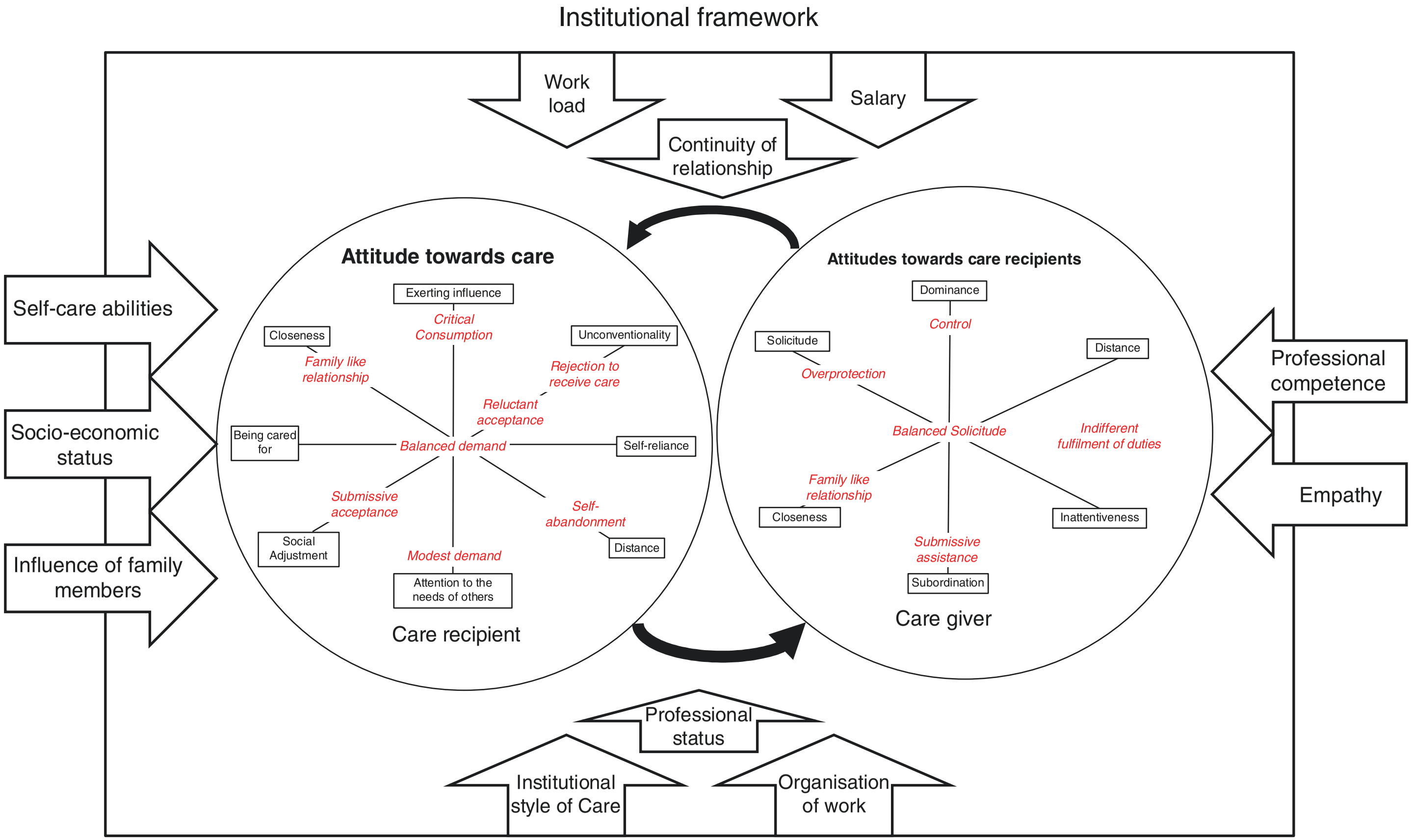

Fig. 7.3 Relationship between caregiver and care recipient within the institutional framework (from: Boggatz (2019). Betreutes Wohnen. Wien: Springer)

qualification was found in developing countries where long-term care facilities resembled poorhouses due to lack of financial resources (Boggatz 2011; Teka and Adamek 2014). Low-qualified staff in assisted living was, however, often supplemented by nursing aids or fully trained nurses who worked as supervisors and were mainly in charge of medical tasks (Ball et al. 2004a; Dobbs 2004). Other facilities just received visits from specialized nurses who came to provide medical treatment or palliative care (Ball et al. 2004a; Cartwright and Kayser-Jones 2003). Staff in nursing homes was often expected to have a better qualification, but even in these facilities there was usually a proportion of low-qualified workers who were involved in providing direct care. In any case, caregivers with a low professional competence worked in a subordinated function and did not feel responsible for complex tasks like nursing assessments or psychological support (Lung and Liu 2016). Such caregivers, however, could compensate their lack of skills with *empathy* which allowed them to establish a family like relationship with the care recipients (Ball et al. 2009). Close relationships with caregivers were often welcome by residents, but for caregivers there was a risk to be absorbed by these relationships and to lose their distance.

The development of the relationship between caregivers and care recipients was to a large extent shaped by economic conditions. Scarce financial resources resulted in understaffing, which in turn created a high workload for caregivers and a lack of time for the care recipients. Almost every study investigated in Chap. 4 reported about such complaints (for example: Ball et al. 2004b; Coughlan and Ward 2007; Hellström and Sarvimäki 2016; Murphy 2007; Tucket 2007; Chuang and Abbey 2009; Williams and Warren 2009; Jordan 2010; Nakrem et al. 2011; Oosterveld-Vlug et al. 2014; Adra et al. 2015; Figueredo-Borda and Zabalegui-Yárnoz 2015; Koskenniemi et al. 2015; Bollig et al. 2016a). Unfavourable working conditions often prevented the establishment of a closer relationship between staff members and the older persons. Caregivers felt forced to work off their duties in a hurry and had no time left for even a short communication. To reduce their workload they were inclined to control the older persons and to enforce their compliance. Only in some facilities there was sufficient time to work in a relaxed atmosphere that allowed closer relationships to be established (Ball et al. 2009; Oosterveld-Vlug et al. 2014). The overall negative situation was exacerbated by low salaries for caregivers, which reflected on the one hand their low qualifications and on the other hand made working in a care facility unattractive (Ball et al. 2009; Andre et al. 2014). High workload and low salaries together resulted in a high turnover of staff (Williams and Warren 2009; Wright et al. 2010). This in turn prevented *continuity in the care relationship* which was a prerequisite to become familiar with each other (Coughlan and Ward 2007; Cooney 2011; James et al. 2014; Oosterveld-Vlug et al. 2014).

The low competence level of caregivers in many facilities required an *organization of work* that was mainly hierarchical. In assisted living facilities, unskilled staff, who was in charge of direct care and had the closest contact to the residents, had to perform a variety of tasks, including meal service, housekeeping, and recreational activities, in addition to assistance with activities of daily living. To fit these workers into the system, they were trained at their workplace and then subjected to constant surveillance (Kuhn 2008). The aim was to teach them a certain code of conduct. They were expected to observe a dress code that was decent according to the tastes of the upper middle class and that prohibited nursing uniforms as they reminded of hospitals (ibid.). It was also in line with the philosophy of assisted living to control the language of the employees and to replace expressions that were common in nursing by others that should reflect the social model of care (instead of the medical model) (Carder 2002; Kuhn 2008). For example, newcomers were instructed by managers in the following way:

> Assisted living and nursing facilities are different things. We're more home-like, less institutional, and we emphasize respect, independence, individuality, and choice. We do not have 'patients,' we have 'residents' or 'tenants.' Think of this as an apartment building. It's a new philosophy that we need to start ingraining. (Carder 2002)

Within this philosophy caregivers had a more servant-like role vis-à-vis residents who felt encouraged to exercise control over them because of their higher social status (Ball et al. 2004a, 2009; Dobbs 2004; Williams and Warren 2009). Extra care housing in the UK, which can be seen as the equivalent to assisted living in the USA, tried to separate personal care and housing support which resulted in the refusal of caregivers to perform lower duties like room cleaning. Such regulations, however, annoyed some residents, since they needed this kind of help and felt they were "paying all this money and they (the caregivers) don't do nothing" (Wright et al. 2010).

Hierarchy was even more pronounced in nursing homes where sometimes up to three different levels of qualification were employed. Beside registered nurses there were auxiliaries and unlicensed assistants whose job titles varied from country to country. At the peak of this system was the management that had mainly administrative tasks. Registered nurses worked on the wards but were often less involved in direct care, focused on medical treatment, prepared and accompanied the physician's round (Adra et al. 2015; Eika et al. 2015) and spent a significant proportion of their time in the office developing written care plans (Bland 2007). Only auxiliaries and care assistants had a closer relationship to the older persons, were more familiar with their needs, but they lacked sometimes the knowledge to interpret signs and symptoms in an appropriate way (Bland 2007; Eika et al. 2015).

This hierarchical system had several negative consequences. Already Gubrium (1997) noted that managers at the top of the hierarchy were committed to an often unrealistic ideal of total care that should embrace the whole person without taking into account the consequences of their directives for those who had to implement them. Caregivers at the bottom of this system paid lip service to these directives, pretended to observe them, and went on following routines they found to be convenient without thinking about them. A hierarchical relationship between registered nurses and assistants could discourage the latter. Since they were perceived to be less competent, their opinion was not heard in the decision-making process and they were instead obliged to follow instructions given by others (Eika et al. 2015). In response to their exclusion from decisions, they abandoned their sense of responsibility and did not share information obtained from their close relationship with the resident since they “were only an assistant” (ibid.). In sum, such a hierarchical system prevented caregivers who were in the position to establish a close relationship to the care recipient from contributing with their knowledge to a person-centred process of care. At the same time, registered nurses who were in charge of planning this process produced paperwork that met the requirements of bureaucracy but not the needs of the older persons (Bland 2007).

Of course, there were also examples of the opposite. Some facilities worked according to the model of primary nursing where each resident was assigned one primary nurse who assumed responsibility to assess, plan, implement, and evaluate care in collaboration with the care recipients and their families. This system could result in closer relationships between nurses, care assistants, and care recipients when nurses worked together with caregivers to give them guidance and feedback on care delivery and established their own close contact with the older persons (Eika et al. 2015). Low hierarchies could also foster team relationships and create an atmosphere of mutual support and encouragement among team members, which in turn had a positive effect on their relationship to older persons (Eika et al. 2015; Nakrem 2015; Canham et al. 2016).

Beside the organization of work, the *institutional style of care* influenced the relationship between caregivers and care recipients. Institutional style of care refers to the patterns of behaviour that are shared by all employees of a facility. These patterns are the manifestation of the institutional culture which is the unwritten law to which everybody adapts. Although not part of any official mission statement, task oriented care seemed to be a common style of care. In order to deal with the workload under the given lack of time, caregiver resorted to routines that allowed them to work off their duties in a fast and efficient way. Finishing the assigned tasks indicated to the staff that the duty of the work shift was complete. The needs of the care recipients, however, were hardly noticed in such a system and building a relationship with them was not considered to be important since it was time consuming and did not yield any direct and measurable benefit. Person-centred care, on the other hand, which was more or less part of every official mission statement, seemed to be an ideal that was hardly found in practice. This does, however, not mean that person-centred care is a product of wishful thinking doomed to fail if facilities tried to implement it. The results of the studies examined in Chap. 4 suggest that, despite adverse circumstances, there were signs of person-centred care that resulted in balanced relationships between caregivers and care recipients. Their limited extent does not indicate that the concept is not feasible in practice. It rather reflects the constraints imposed by economy on the care of the older persons that need to be criticized. As long as care is evaluated according to the criteria of efficiency and cost-effectiveness, the possibilities for person-centred care will remain limited and caregivers may only implement this idea with a high degree of self-sacrifice. They are expected to meet moral standards desired by society but unknown to economy that determines their conditions of work. This contradiction defines the role that caregivers had and still have to perform.

Both the organization of work and the institutional style of care that were shaped by economic constraints had a significant influence on the *professional status* of caregivers which in turn influenced their relationship with the care recipients. A hierarchical system favoured a task oriented care since this approach to care just required working off some prescribed duties. At the same time, it reinforced the servant-like role of the caregivers vis-à-vis the older persons which in turn resulted in a low recognition of their work (Ball et al. 2009). Low recognition was a further factor that contributed to a high staff turnover. Such a system tended to exclude those who had a chance for better work, while those who no longer had that chance remained in it. On the other hand, the opportunity of self-directed work entails a higher degree of job satisfaction. Professional autonomy is the prerequisite for person-centred care. It gives caregivers and nurses the freedom to shape their relationship with the care recipient. If they are self-determined actors rather than persons who follow the instructions of others, they may also gain social recognition of their work. The precondition for such a professional autonomy is of course a high level of qualification. Each society has to decide how much it values care for the older persons and how much it is willing to spend on it. The value a society attaches to care is expressed in the education and professional status of the caregivers.

7.3 Person-Centred Care: A Pathway to the Person

To conclude this chapter we shall summarize the principles of person-centred care as they became apparent in the previous chapters. These principles can be considered as the foundation of professional care. Person-centred care is the required response to older person’s quest for quality of life. However, quality of life is not an outcome that can be produced by some kind of industrial process. It rather arises from an inner balance that older persons have to find within themselves. Quality of life is thus not subject to the control of caregivers who could determine from the outset of the care process a desirable degree of quality, to be measured after the implementation of care interventions. Such an understanding of care is involved in the institutional style of task oriented care. This style may manifest itself as control or overprotection. The German philosopher Heidegger described the latter as a mode of solicitude in the following way: “It can, as it were, take away ‘care’ from the Other and put itself in his position in concern: it can leap in for him. […] In such solicitude the Other can be become one who is dominated and dependent, even if this domination is a tacit one and remains hidden from him” (Heidegger 1962, p. 158).

In person-centred care, however, caregivers have to engage in a relationship with the care recipient. Instead of deciding for them, they have to be attentive and listen to their needs. This does not mean that they should subordinate themselves to the care recipients and allow them to determine their actions. Person-centred care is not based on a servant-like role. It rather requires an inner balance between closeness and distance, solicitude and inattentiveness, and exerting influence on and paying attention to the needs of the care recipients. This balance on the side of the caregiver in turn provides the care recipient with the opportunity to find his inner balance. According to Heidegger, this balance may result in “a kind of solicitude which does not so much leap in for the Other as leap ahead of him in his existential potentiality of being, not in order to take away his 'care' but rather to give it back to him authentically […] it helps the Other to become transparent to himself in his care and to become free for it." (ibid.) This freedom does not mean that care recipients may do and demand whatever they like. Rather, caregivers and nurses can make them aware of the possibilities in a particular situation and thus enable them to make their own decisions and to find out what is really meaningful for them.

This way of care evolves from a dialogue. It presupposes that both sides get to know each other without restrictions by a predefined purpose. This does not only require time, but also a way of communication that is not goal-oriented. Care recipients will only engage in a relationship if their self-determination is respected and caregivers do not try to control their behaviour. Allowing the other person to be what she is gives her the chance to get involved in the relationship. Although such a dialogue does not have a predefined goal, it does not happen unintentionally. Both sides will only enter into dialogue if they each have their own concerns. The interplay of these concerns then gives rise to the direction of their dialogue. Although the dialogue is not targeted at a fixed endpoint, it does not meander aimlessly. Whatever his goal was, however, only becomes clear when both sides agree that it has been achieved.

Person-centred care is therefore a process of gradual rapprochement. It is based on a dialogue, but getting to know the other also requires sensitivity for what remains unspoken. Persons are often not aware of the habits that determine their behaviour and self-concealment is also a part of their personality. Therefore a variety of methods to understand the older person are required, as shown in Fig. 7.4.

The process of rapprochement should take place within the framework of primary nursing where one caregiver or nurse has the main responsibility for its implementation. It starts with an initial assessment of needs that routinely occurs when caregivers and care recipients meet for the first time at admission. It involves a dialogue with the family which is a valuable source of information about habits and needs that remain sometimes unspoken. A biographical interview may provide a deeper understanding of the personal background of the care recipients. Team discussions may further complement the existing knowledge about them. They can reveal conflicting perceptions of individual team members, and their resolution is likely to result in better coordination of care. Care should eventually be planned and evaluated in dialogue with the care recipients. In addition, observation throughout the process of care may provide further clues to what is not apparent at a first glance. Each method shows a partial aspect of the whole person, which can be gradually combined like parts of a puzzle into a more or less complete picture.

The aim of this process is to understand the character of the older persons. Because they follow habits, caregivers should identify typical patterns of their behaviour. These patterns can be described with the help of the orientations of action that have been identified in this book as the constitutive dimensions of quality of life in old age. Since the various orientations of action are interrelated, caregivers may create a personality profile on the basis of their individual manifestation and assess the extent to which the orientations of central concern are satisfied. Since older persons experience crises that threaten the satisfaction of their essential needs, they have to cope with these threats and may need to change their habits. Nurses and caregivers should

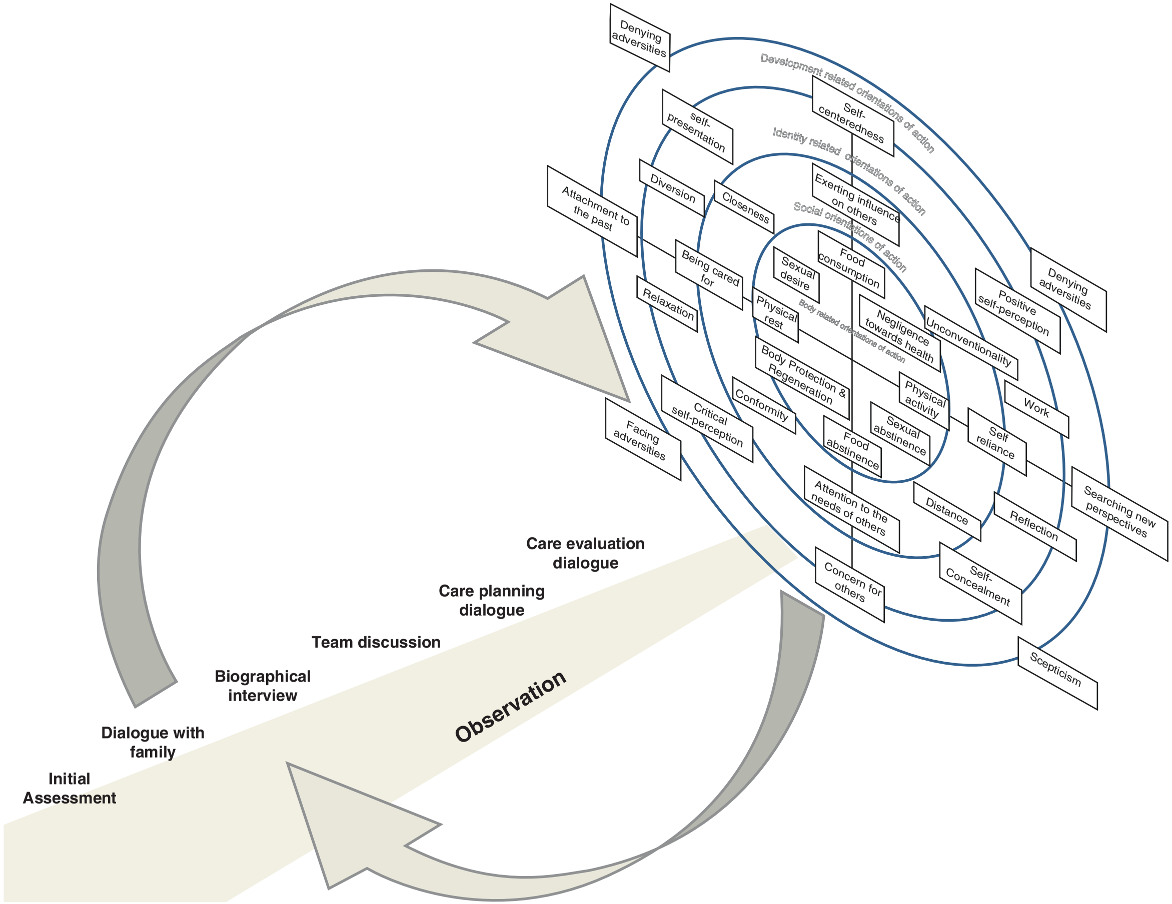

Fig. 7.4 A pathway to the person

therefore not limit themselves to identifying typical habits and routines, but should also explore a person's possibilities and resources for change. Although they cannot dictate any change, they can make the older persons aware of their options. In this way they can accompany their inner struggle to regain their lost balance and encourage appropriate behavioural and attitudinal reactions. This is, however, not a one-sided process that is only initiated and determined by caregivers and nurses. It requires a willingness on their part to learn from the older persons how to deal with ageing and dying and how they can support them in this process as caregivers. If they want to influence the older persons, they in turn have to accept to be influenced by them, so that neither side is dominated by the other. In its truest sense, person-centred care therefore means being in a balanced relationship with the recipient of care.

References

Adra MG, Hopton J, Keady J (2015) Constructing the meaning of quality of life for residents in care homes in the Lebanon: perspectives of residents, staff and family. Int J Older People Nursing 10:306–318

Améry J (1994) On aging: revolt and resignation. Indiana University Press, Bloomington

Andersson M, Hallberg IR, Edberg A-K (2008) Old people receiving municipal care, their experiences of what constitutes a good life in the last phase of life: a qualitative study. Int J Nurs Stud 45:818–828

Andre B, Sjovold E, Rannestad T, Ringdal GI (2014) The impact of work culture on quality of care in nursing homes-a review study. Scand J Caring Sci 28:449–457

Aristotle (1999) Nicomachean ethics. Translated by WD Ross. Batoche Books, Kitchener

Backman K, Hentinen M (1999) Model for the self-care of home-dwelling elderly. J Adv Nurs 30(3):564–572

Ball MM, Perkins MM, Whittington FJ, Connell BR, Hollingsworth C, King SV (2004a) Managing decline in assisted living: the key to aging in place. J Gerontol B Psychol Sci Soc Sci 59(4):202–212

Ball MM, Perkins MM, Whittington FJ, Hollingsworth C, King SV, Combs BL (2004b) Independence in assisted living. J Aging Stud 18(4):467–483

Ball MM, Lepore ML, Perkins MM, Hollingsworth C, Sweatman M (2009) They are the reason I come to work: the meaning of resident-staff relationships in assisted living. J Aging Stud 23(1):37–47

Behr A, Meyer R, Holzhausen M, Kuhlmey A, Schenk L (2013) Die Intimsphäre. Eine wichtige Dimension der Lebensqualität von Pflegeheimbewohnern Zeitschrift für Gerontologie und Geriatrie 46:639–644

Bergland A, Kirkevold M (2006) Thriving in nursing homes in Norway: contributing aspects described by residents. Int J Nurs Stud 43:681–691

Bland M (2007) Betwixt and between: a critical ethnography of comfort in New Zealand residential aged care. J Clin Nurs 16:937–944

Boggatz T (2011) Growing old in Egypt. American University Press of Cairo, Cairo

Boggatz T (2019) Betreutes Wohnen. Perspektiven zur Lebensgestaltung bei Bewohnern und Betreuungspersonal. Springer, Heidelberg

Boggatz T, Tamer F, Mohammedin A, Dassen T (2009) Attitudes of Egyptian nursing home residents towards staying in a nursing home - a qualitative study. Int J Older People Nursing 4(4):242–253

Bollig G, Gjengedal E, Rosland JH (2016a) Nothing to complain about? Residents' and relatives' views on a "good life" and ethical challenges in nursing homes. Nurs Ethics 23:142–153

Bollig G, Gjengedal E, Rosland JH (2016b) They know!-do they? A qualitative study of residents and relatives views on advance care planning, end-of-life care, and decision-making in nursing homes. Palliat Med 30:456–470

Bowers BJ, Fibich B, Jacobson N (2001) Care-as-service, care-as-relating, care-as-comfort: understanding nursing home residents' definitions of quality. The Gerontologist 41:539–545

Bowers H., Clark A., Crosby G., Easterbrook L., Macadam A., MacDonald R., MacFarlane A., MacLean A., Patel M., Runnicles D., Oshinaike T., Smith C. (2009). Older people's vision for long-term care. York: Joseph Rowntree Foundation. Available at: https://www.jrf.org.uk/report/older-peoples-vision-long-term-care.

Canham SL, Battersby L, Fang ML, Sixsmith J, Woolrych R, Sixsmith A (2016) From familiar faces to family: staff and resident relationships in long-term care. J Aging Health 29(5):842–857. https://doi.org/10.1177/0898264316645550

Carder PC (2002) The social world of assisted living. J Aging Stud 16:1–18

Cartwright J, Kayser-Jones J (2003) End-of-life care in assisted living facilities: perceptions of residents, families, and staffs. J Hosp Palliat Nurs 5:143–151

Chang SJ (2013) Lived experiences of nursing home residents in Korea. Asian Nurs Res 7:83–90

Chuang Y-H, Abbey J (2009) The culture of a Taiwanese nursing home. J Clin Nurs 18:1640–1648

Cooney A (2011) 'Finding home': a grounded theory on how older people 'find home' in long-term care settings. Int J Older People Nursing 7:188–199

Coughlan R, Ward L (2007) Experiences of recently relocated residents of a long-term care facility in Ontario: assessing quality qualitatively. Int J Nurs Stud 44:47–57

Cumming E, Henry WE (1961) Growing old. The process of disengagement. Basic Books, New York

Dees MK, Vernooij-Dassen MJ, Dekkers WJ, Vissers KC, van Weel C (2011) 'Unbearable suffering': a qualitative study on the perspectives of patients who request assistance in dying. J Med Ethics 37:727–734

Dobbs D (2004) The adjustment to a new home. J Hous Elder 18:51–71

Eika M, Dale B, Espnes GA, Hvalvik S (2015) Nursing staff interactions during the older residents' transition into long-term care facility in a nursing home in rural Norway: an ethnographic study. BMC Health Serv Res 15:125. https://doi.org/10.1186/s12913-015-0818-z

Figueredo-Borda N, Zabalegui-Yárnoz A (2015) Long-term care of the elderly in Uruguay. J Transcult Nurs 26:178–184

Fleming J, Farquhar M, Brayne C, Barclay S (2016) Death and the oldest old: attitudes and preferences for end-of-life care qualitative research within a population-based cohort study. PloS One 11:e0150686

Gubrium JF. (1997). Living and Dying at Murray Manor. Charlottesville: University Press of Virginia

Harmer BJ, Orrell M (2008) What is meaningful activity for people with dementia living in care homes? A comparison of the views of older people with dementia, staff and family carers. Aging Ment Health 12:548–558

Hauge S, Kristin H (2008) The nursing home as a home: a field study of residents' daily life in the common living rooms. J Clin Nurs 17:460–467

Havighurst RJ (1961) Successful Aging. The Gerontologist 1(1):8–13

Heidegger M (1962) Being and time. HarperCollins, New York

Hellström U W, Sarvimäki, A (2016) Experiences of Self-Determination By Older Persons Living in Sheltered Housing. Nursing Ethics 14 (3):413-424

Iwasiw C, Goldenberg D, McCutcheon S, Bol N (1996) Residents' perspectives of their first 2 weeks in a long-term care facility. J Clin Nurs 5:381–388

Iwasiw C, Goldenberg D, Bol N, McMaster E (2003) The first year in a long-term care facility. J Gerontol Nurs 29(1):45–54

James I, Blomberg K, Kihlgren A (2014) A meaningful daily life in nursing homes - a place of shelter and a space of freedom: a participatory appreciative action reflection study. BMC Nurs 13:19

Jordan LG (2010) The perceptions of nursing team caring behaviors among residents of an assisted living facility for retired veterans. Dissertation, The Catholic University of America, Washington DC

Josat S (2005) Welche Qualitätskriterien sind Angehörigen in der stationären Altenpflege wichtig? Eine Einzelfallstudie. Pflege 18:169–175

Koch-Straube U (2003) Fremde Welt Pflegeheim. Huber, Bern

Koskenniemi J, Leino-Kilpi H, Suhonen R (2015) Manifestation of respect in the care of older patients in long-term care settings. Scand J Caring Sci 29:288–296

Kuhn MG (2008) The eye of beauty: creating a place for elite and aging elders. Dissertation, The University of Arizona, Tucson

Lambert HC, McColl MA, Gilbert J, Wong J, Murray G, Shortt SED (2005) Factors affecting long-term-care Residents' decision-making processes as they formulate advance directives. The Gerontologist 45:626–633

Lung C-C, Liu JYW (2016) How the perspectives of nursing assistants and frail elderly residents on their daily interaction in nursing homes affect their interaction: a qualitative study. BMC Geriatr 16:13

Murphy K (2007) A qualitative study explaining nurses' perceptions of quality care for older people in long-term care settings in Ireland. J Clin Nurs 16:477–485

Naess A, Fjaer EG, Vabo M (2016) The assisted presentations of self in nursing home life. Soc Sci Med 150:153–159

Nakrem S (2015) Understanding organizational and cultural premises for quality of care in nursing homes: an ethnographic study. BMC Health Serv Res 15:508. https://doi.org/10.1186/s12913-015-1171-y

Nakrem S, Vinsnes AG, Seim A (2011) Residents' experiences of interpersonal factors in nursing home care: a qualitative study. Int J Nurs Stud 48:1357–1366

Nakrem S, Vinsnes AG, Harkless GE, Paulsen B, Seim A (2013) Ambiguities: residents' experience of nursing home as my home. Int J Older People Nursing 8:216–225

Oakes CE, Sheehan NW (2012) Autonomy in assisted living: employees' perspectives. J Hous Elder 26:317–337

Oosterveld-Vlug MG, Pasman HRW, van Gennip IE, Willems DL, Onwuteaka-Philipsen BD (2013) Nursing home staff's views on residents' dignity: a qualitative interview study. BMC Health Serv Res 13:353

Oosterveld-Vlug MG, Pasman HRW, van Gennip IE, Muller MT, Willems DL, Onwuteaka-Philipsen BD (2014) Dignity and the factors that influence it according to nursing home residents: a qualitative interview study. J Adv Nurs 70:97–106

Rowe JW, Kahn RL (1987) Human aging: usual and successful. Science 237(4811):143–149

Shaw R L, West K, Hagger B., Holland C.A, (2016) Living well to the end: A phenomenological analysis of life in extra care housing. International Journal of Qualitative Studies on Health and Well-being 11: 31100

Sidenvall B (1999) Meal procedures in institutions for elderly people: a theoretical interpretation. J Adv Nurs 30:319–328

Teka A, Adamek ME (2014) "We prefer greeting rather than eating:" Life in an elder care center in Ethiopia. J Cross Cult Gerontol 29:389–404

Tsai H-H, Tsai Y-F (2008) A temporary home to nurture health: lived experiences of older nursing home residents in Taiwan. J Clin Nurs 17:1915–1922

Tucket AG (2007) The meaning of nursing-home: 'Waiting to go up to St. Peter, OK! Waiting house, sad but true' - an Australian perspective. J Aging Stud 21:119–133

Tuominen L, Leino-Kilpi H, Suhonen R (2016) Older people's experiences of their free will in nursing homes. Nurs Ethics 23:22–35

Walker H, Paliadelis P (2016) Older peoples' experiences of living in a residential aged care facility in Australia. Australas J Ageing 35:E6–E10

Westin L, Danielson E (2007) Encounters in Swedish nursing homes. A hermeneutic study of residents' experiences. J Adv Nurs 60:172–180

Whitaker A (2010) The body as existential midpoint—the aging and dying body of nursing home residents. J Aging Stud 24:96–104

Williams KN, Warren CAB (2009) Communication in assisted living. J Aging Stud 23:24–36

Wright F, Tinker A, Mayagoitia R, Hanson J, Wojgani H, Holmans A (2010) What is the 'extra' in extra care housing? Br J Soc Work 40:2239–2254