Quality of Life in the Process of Dying

6

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.

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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

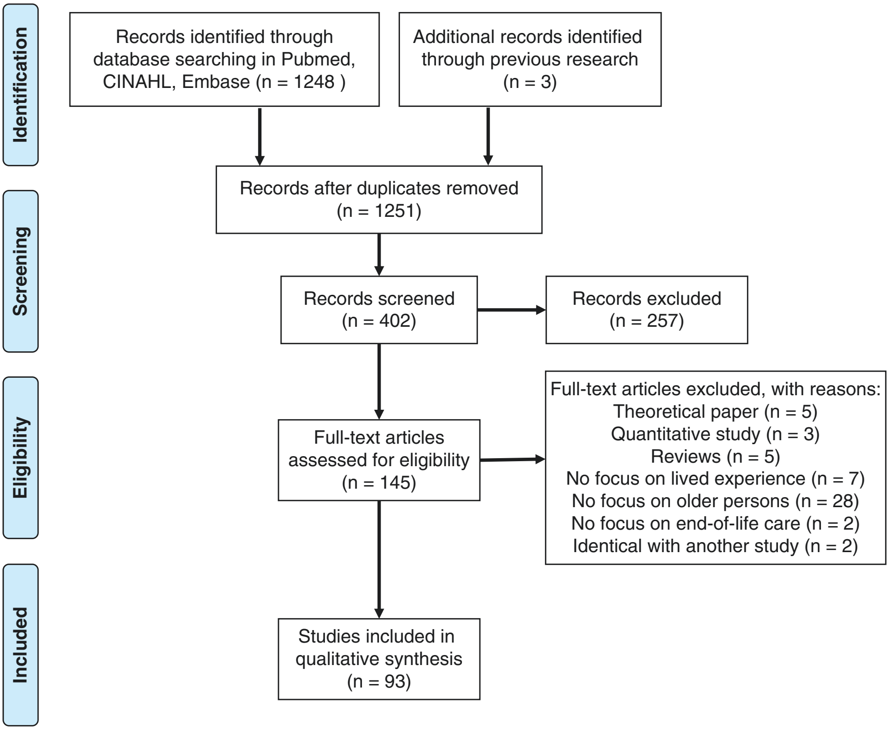

Fig. 6.1 Earch strategy according to PRISMA (Moher et al. 2009)

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,

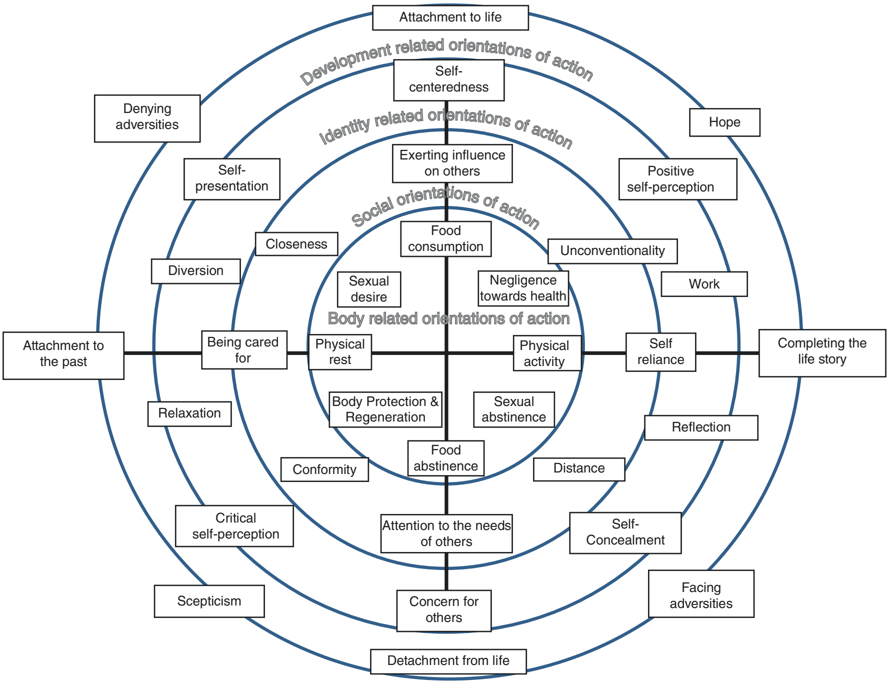

Fig. 6.2 The complete model of orientations of actions

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.

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