Psychosocial Interventions

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Abstract

In section A, we focus on the use of the adaptation-coping model as a theoretical and practical framework in the care for persons with dementia in combination with integrated emotion-oriented care in the different phases of dementia. First of all, we address the adaptation-coping model and the main principles and method of integrated emotion-oriented care. We subsequently discuss a number of adaptive tasks that elderly people with dementia can be confronted with. We describe how these adaptive tasks can cause disruptions in the functioning or in behavior and mood. We then examine to what extent integrated emotion-oriented care attempts to prevent, reduce, or eliminate these disruptions and what the expected effect is on the behavior and mood of the person with dementia.

In section B we will look at the implementation of psychosocial interventions to residents with dementia in nursing homes. We begin by looking at theory that aids in furthering our insights into the importance of building a trusting relationship with nursing home residents. Building on trust, we will explore Erickson's theory as it relates to aging. Here, we will discuss several types of interventions and mediums that have shown significant and enduring success with older adults.

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4.1 Section A: Coping with Dementia – Integrated Emotion-Oriented Care for Nursing Home Residents[1]

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4.1.1 The Adaptation-Coping Model

Elderly people with dementia who have been institutionalized in a psychogeriatric nursing home may experience the consequences of their disease and their changed living conditions (stay at the nursing home, loss of independence, etc.) as stressful. The adaptation-coping model (Dröes 1991) provides a framework from which the problems of the person with dementia can be viewed. It offers aids for diagnosis, for the treatment and evaluation of the psychosocial problems of elderly people with dementia.

The adaptation-coping model is based on the coping theory formulated by Lazarus and Folkman (1984) and the adaptive tasks distinguished by Moos and Tsu (1977) for chronic illness. Dröes (1991) operationalized the model for psychosocial care for elderly people with dementia. One of the most important starting points of the adaptation-coping model is people's constant striving for balance. When people are confronted with changes in their existence, this unavoidably leads to a disruption of the existing balance. By coping with these changes consciously, but even more often unconsciously, they try to regain a balance. Moos and Tsu (1977) indicate that in general seven adaptive tasks are important for the restoration of the disrupted balance. The difficulty the individual patient experiences with the various adaptive tasks is determined in part by his personality and life history. Furthermore, illness-related problems and social and material circumstances also have an effect. According to Dröes (1991), the adaptive tasks distinguished by Moos and Tsu, the adaptation process they describe, and the factors that influence this process also apply to people with dementia. Dröes (1991) describes in detail which coping strategies people with dementia appear to use when they are coping with the different adaptive tasks. She indicates how various behavior and mood problems, such as aggressive, depressed, and anxious behavior, inactivity, and socially isolated

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[1] This chapter is adapted from Finnema EJ, Van der Kooij CH, Dröes RM (2015) Omgaan met dementie: belevingsgerichte begeleiding en zorg in de verschillende stadia van dementie. In: Dröes RM, Schols J, Scheltens Ph (ed) Meer Kwaliteit van Leven. Integratieve Persoonsgerichte Dementiezorg. Leusden: Diagnosis Uitgevers, p 163–185.

Table 4.1 Adaptive tasks related to nursing home residents with dementia

Adaptive tasks	Adaptive domains
Coping with own invalidity	Cognitive adaptation
Developing an adequate relationship with the staff	
Maintaining an emotional balance	Emotional adaptation
Maintaining a positive self-image	
Preparing for an uncertain future	
Coping with the nursing home environment	Social adaptation
Developing and maintaining social relationships	

behavior, should perhaps be interpreted as (in some cases not quite adequate) coping behavior. In her opinion, a reduction of these behavior and mood problems indicate a reduction of experienced stress and psychosocial problems, and that would be proof of better adaptation. Depending on the adaptive tasks on which improvement is observed, one can say there has been cognitive or mental, emotional, or social adaptation (see Table 4.1).

Dröes' description of coping strategies is based on Verwoerdt (1976) and Lazarus and Folkman (1984). Verwoerdt described various defense mechanisms in people with dementia, namely, strategies aimed at management and control such as intellectualization; separation of reason and emotion; certain obsessive-compulsive mechanisms; overcompensation and counterphobic behavior; strategies to keep the threat outside consciousness, such as suppression, denial, rationalization, projection, and introjection; and regressive strategies, such as regressive behavior, giving up, and withdrawal.

Lazarus and Folkman (1984) made a distinction between problem-oriented and emotion-oriented coping strategies. Problem-oriented strategies focus on resolving the problems that have caused tension and on restoring a sense of control. Examples are analytical strategies, such as searching for relevant information and thinking up solutions, "(...) but also strategies that focus on the individual in question, such as motivational or cognitive changes, changing the level of aspiration, mental preparation for the consequences of the disease, finding alternative ways of fulfillment and learning new skills (...)" (Dröes 1991, p. 43). Emotion-oriented strategies focus primarily on reducing the emotional tension that is caused by the consequences of the disease. Examples are "avoiding behavior, selective attention, reinterpretation of the situation and behavior strategies, such as (...) meditation, alcohol consumption, expressing anger and looking for emotional support and reassurance" (Dröes 1991, p. 43).

In most situations, people use a combination of problem-oriented and emotion-oriented strategies according to Lazarus and Folkman (1984). However, when the stress situation is appraised as impossible to control or influence (as may happen in the case of serious illness), people generally tend more toward emotion-oriented ways of coping.

Although there is a clear distinction between the various adaptive tasks in theory, it is not always possible in everyday practice to infer from the way in which he behaves with which adaptive task the elderly person with dementia has a problem.

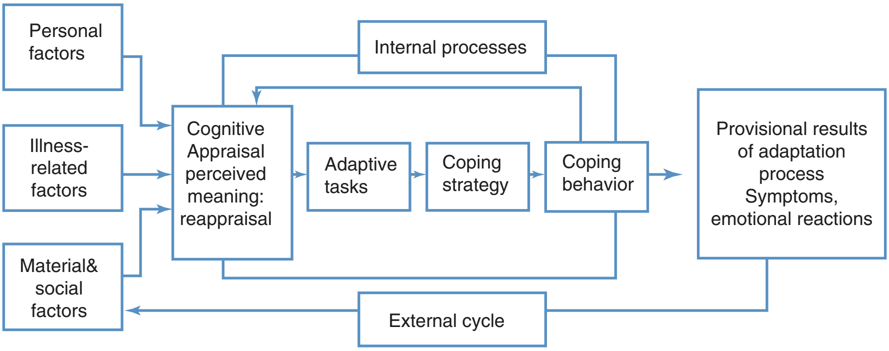

Fig. 4.1 The Adaptation-coping model (Dröes 1991)

A correct interpretation of the behavior (Dröes refers to this as "psychosocial diagnosis") is therefore always based on a combination of knowledge about the person, his life history, his personal experience of the situation and his functional abilities, an analysis of the social and material circumstances in which the behavior occurs, and an understanding of the coping strategy (strategies) he uses.

In view of all this, it is obvious that the adaptation process is complex and dynamic, and also interactional, i.e., the continuous interaction with the environment affects the coping behavior (external cycle). This creates an opening for the environment to influence disruptions in behavior and mood by means of, among other things, emotion-oriented care and other treatment and support methods. Several studies confirm the "stress-coping" notion (Moore 1997). The problems indicated by people with dementia were related first of all to their own cognitive deterioration and the disabling effects this had on their everyday functioning. In addition, the problems referred to the emotional burden and social consequences of the disease for themselves as well as their environment. People with dementia indicated, for example, that it is difficult to become dependent on others and to stay in touch with friends and acquaintances (Cohen 1991; Dröes 1991; Kiyak and Borson 1992; Cotrell and Schulz 1993; Cotrell and Lein 1993). An indication for the experience of stress in dementia from neurobiological research is that several stress-regulating systems in our body prove to be highly activated in Alzheimer's disease (Hoogendijk 1998) (Fig. 4.1).

4.1.2 Integrated Emotion-Oriented Care

In practice, the term emotion-oriented care is used as a collective name for approaches that try to link up with the experiences and perceptions of the person with dementia (Finnema et al. 2000a, b). Emotion-oriented care approaches include:

- The validation approach (Feil 1989a, b), which aims at empathizing with the emotions and perceptions of the people with dementia and validating their feelings

- Reminiscence, which uses objects, old photographs, and utensils (Rossaert 1989; Thornton and Brotchie 1987)
- Sensory activation, i.e., attempting to make contact through various senses by means of sounds, smells, and hugs (Achterberg and Kok 1992)
- Reality orientation, which aims to support the cognitive functioning of the person with dementia and therefore his sense of control, through training, offering structure, clear timetables, and aids, such as a photograph on the bedroom door and other reference points in the environment (Spector et al. 2012)
- Passivities of daily life (PDL), which pays attention to comfortable sitting or lying positions and passive relaxation exercises and which is based in part on haptonomic principles (Eijle and Van der Wulp 1988; Rabe 1993)

The integrated emotion-oriented care approach strives for an application of (suitable elements from) the emotion-oriented approaches mentioned, integrated in the daily care. Our starting point is the definition of integrated emotion-oriented care as formulated by Van der Kooij (2003, 2013, 2016):

> “Integrated emotion-oriented care is the integrated application of emotion oriented approaches and communicative skills, customized to the individual person with dementia, taking into account his needs and physical and mental disabilities, for the purpose of offering feelings of security and trust to the person with dementia and helping him to adjust to the consequences of his illness.”

Nowadays, it is generally accepted that there are no standard prescriptions for the way caregivers should communicate with people with dementia. In every situation, it is necessary to tune into the unique personality of the person with dementia, his particular personality, his situation, his life history, his needs, and his way of coping with the disease. The most important question for the caregiver is not whether a particular method was applied as described, but whether there was a situation or a moment of mutual understanding and contact (Halek and Bartholomeyzcik 2006). Integrated emotion-oriented care focuses on the awareness of and reflection on the “moments of contact” and on building up an emotional relationship with the person with dementia (Van der Kooij 2003, 2016).

4.1.2.1 Phases of Ego-Experience and Perceptions

Little is known about how people perceive themselves during the dementia process. Integrated emotion-oriented care starts from four subsequent phases of “Ego-experience”: threatened Ego-experience, wandering Ego-experience, hidden Ego-experience, and sunken Ego-experience (Van der Kooij 2003, 2016). These phases are based on the phases of dementia as described earlier by Verdult (1993) and on Feil’s (1989a, b) four stages of disorientation: orientation problems, confusion in time, repetitive movement, and vegetation.

During the phase of *threatened Ego-experience*, people lose their grip on themselves and their environment. They start having trouble remembering and thinking. People they know appear to be strangers, familiar spaces are unknown, and the secure feeling about self in the continuity of past, present, and future is uprooted. The degree in which people are aware of the problems as a result of their dementia varies.

During the phase of *wandering Ego-experience*, the person with dementia gets lost, as it were, in an individual reality. The chronology of his past erombles, and he loses the ability to arrange and name his perceptions.

The *hidden Ego-experience* is characterized by apparent isolation and inaccessibility. It seems like the person with dementia resides in a personal, inner, timeless world where he doesn't need anyone and won't allow anyone in. Making contact is still, however, possible.

In the *sunken Ego-experience*, the person with dementia no longer responds to his environment; there seems to be no more interaction of feelings.

To gain some understanding of the experiences and perceptions of the person with dementia, an assessment is made of the Ego-experience phase, as well as how he experiences his current situation and how his life history influences his experience of the present. Experiencing the current situation refers to how the dementing person copes with, and experiences, the consequences of his illness and his institutionalization in the nursing home (cf. Dröes 1991).

4.1.2.2 Care Needs and Care Objectives

The different phases of Ego-experience in integrated emotion-oriented care are distinguished to provide caregivers with a frame of reference to help assess the individual care needs of people with dementia. Five general care needs are distinguished (Van der Kooij 2003), which are derived from Maslov's (1972) hierarchy of needs and which have been modified for dementia on the basis of descriptions by, among others, Feil (1984), and Kitwood and Bredin (1992). The care needs concern being able to meet basic physical needs, security, trust and structure, contact and connectedness, self-respect, and self-realization. The general care objectives are in line with these care needs and are described as accepting dependence, experiencing security, experiencing connectedness, experiencing appreciation, and experiencing affirmation or even validation.

4.1.2.3 Methods in the Different Phases of Dementia and Phases of Ego-Experience

Although the care needs and care objectives are, to a greater or smaller extent, relevant to every phase of Ego-experience, they require different methods during different phases. Starting point for action and making contact is always the perception and experience of the person with dementia. Van der Kooij has distinguished six areas of experience: sensory, rational, emotional, physical, social, and spiritual experience. This classification of areas of experience is based in part on the stimulation of the general psychological functions "perception, thinking, and feeling," as they are given shape in sensory activation, the reality orientation

Table 4.2 Integrated emotion-oriented care in relation to adaptive tasks

Adaptive task	Integrated emotion-oriented care
Coping with own invalidity	Help the person with dementia to cope with the constraints. Support him and encourage him to do the things he still can
Developing an adequate care relationship with the staff	Behave empathetic and make use of knowledge of the life history of the person with dementia. Accept the resident as the person he was and is today
Maintaining an emotional balance	Respect emotions and confirm or weak them off. Offer pleasant sensory stimuli (music, good food, etc.)
Maintaining a positive self-image	Promote the dignity of the person with dementia to let him remember positive events and encourage him to do activities that he can
Preparing for an uncertain future	Show understanding for the feelings of the person with dementia about present and future and offer activities that make it here and now makes sense
Coping with the nursing home environment	Let the person with dementia feel at home and continue to maintain his habits to prevent hospitalization. Involve the person with dementia in recreational activities
Developing and maintaining social relationships	Match the needs of individual contacts and encourage the person with dementia to fulfill several social roles

approach, and the validation approach, respectively. As the body of the person with dementia is frequently "touched" in caring and nursing contact, Van der Kooij made experience of the own body a separate field of attention in care. One approach that integrated emotion-oriented care derives techniques from in this area is the method passivities of daily life (PDL), a method that was developed by Dutch physiotherapists (Eijle and Van der Wulp 1988). In the German-speaking Europe, this is known as Basale Stimulation (Fröhlich 1991). Van der Kooij derived the experience areas social and spiritual experience from Maslov's hierarchy of needs (Maslov 1972). Social experience refers to making contact. In this context techniques from the validation approach and reminiscence are used. Spiritual experience refers to self-realization, signification, and achieving or not achieving ego integrity. Techniques from reminiscence and the validation approach are used here (Table 4.2).

4.1.2.4 Care in the Phase of Threatened Ego-Experience

Acceptance of Dependency People in the phase of the threatened Ego-experience are generally quite able, in their own way, to take care of themselves. For that reason, caregivers take over actions, very tactfully, only when necessary. They also look for opportunities to offer options.

Experiencing Security and Trust An important goal during this phase is to make the person with dementia experience control. Someone who feels threatened looks for security. There are various ways of helping the person with dementia in this respect: offering clearly organized options, a warm (small-scale) living environment, a fixed schedule, maintaining familiar rules of conduct, a place of one's own, supporting the dementing person's norms and values, developing and/or maintaining rituals and common practices (e.g., drinking coffee or reading the newspaper in a small group every morning), and making sure there are plenty of reference points, such as photographs and objects around someone's bed, personal toiletries, and a personal chair in the living room. These are ways of creating an organized and structured environment.

Experiencing Connectedness People in the threatened Ego-experience appear to keep others at a distance. This is often caused by fear, anger, or feelings of loneliness. Emotion-oriented care is based on the notion that these people need others to feel safe and to make contact. This can be done in many ways, for example, by radiating security and closeness. The caregiver can furthermore mirror the attitude of the person with dementia. His body language, eyes, and voice manifest tension, anger, or anxiety. By showing security, interest, and respect during the mirroring, the chances that the person feels understood are increased. This provides a basis for contact.

Experiencing Appreciation The sense of self-worth is enhanced by appealing to personal qualities in a day program or week program, by activating familiar actions and social roles, and by asking people to do things like read to others, help with domestic or household activities, and advise or console another resident.

Experiencing Affirmation and Validation In this phase, the person with dementia experiences himself as before and makes frenetic efforts to keep it that way. Caregivers can support the person with dementia by behaving "normally," not correcting or confronting, and providing support only when necessary.

4.1.2.5 Care in the Phase of Wandering Ego-Experience

Accepting Dependence Lost abilities require a prothetic approach and environment, a gradual taking over of actions that lead to fear of failure and a reduction of complexity. Supporting the memory of the person with dementia requires tact on the part of the caregiver. Sometimes the person with dementia will appreciate this; other times, he will hold onto his own reality. In this phase, it is pointless to enter into discussion about facts or words. This makes the person with dementia feel corrected and patronized.

Experiencing Security and Trust The person with dementia derives control from structure, familiar faces, spaces, rituals, objects, reference points on the ward (Holden 1983; Hanley 1981; Hanley et al. 1981), and support of the ability to make one's own choices and decisions.

Experiencing Connectedness Making contact with people in the wandering Ego-experience phase is often still possible. People in this phase take the initiative to make contact. If the reaction is positive, a reciprocity and interaction of feelings develop. During this phase, the person can make very apt remarks and does not let conventions limit him anymore. Word finding problems do not stop him from having conversations. The discussion partner only helps to keep the conversation on track and offers words, draws conclusions, or summarizes what has been discussed (Feil 1989a, b, 1992). In this, the partner needs to be both empathic and prothetic.

Experiencing Appreciation For people in this phase, life themes and losses play an important part in their experience of reality. These themes are discussed individually as well as in groups. This may bring about a sense of (delayed) validation, understanding, compensation, or satisfaction. Whether the person experiences his reality positively or negatively depends to a great extent on the person and his life history. If someone has not built up a positive self-perception during his life and has known few good relationships, the behavior in this phase can be difficult to manage.

Experiencing Affirmation and Validation The perception of the own identity becomes fragmented due to gaps in the memory. Caregivers can validate the feeling of identity of the person with dementia by addressing him in his identity and by incorporating, whenever possible, satisfying activities from the past into his current life in the nursing home (e.g., helping with the dishes, folding the laundry, polishing the silver or brass). In general, this will make the dementing person feel appreciated. Some caution is required, however. An excessive appeal on who one used to be, what one was able to do, or what brought pleasure in the past can also be very confrontational in the current situation.

4.1.2.6 Care in the Phase of Hidden Ego-Experience

Accepting Dependence During this phase, the person is totally dependent on others. The person with dementia is likely to accept this more easily if he trusts those others. Caregivers need to build up this trust, e.g., by always carrying out care actions in the same way and by making themselves recognizable by means of the tone of voice, type of greeting, and physical contact. Despite the fact that one is dependent, experiencing the freedom to choose is still very important. Selecting the moments and ways in which choices are offered to the person with dementia requires creativity and tact.

Experiencing Connectedness In this phase, the person depends on the initiatives of others for contact. Many people in this stage of dementia are, however, still open to liveliness, cheerfulness, humor, music, and movement (Buckwalter et al. 1995). Caregivers need to be alert to this in their contacts and in offering activities. Mirroring body posture and movements may help to tune oneself to the feelings of the person with dementia and invite him to share those feelings. Sometimes, eye contact helps to make the person with dementia experience closeness and intimacy; sometimes, sitting with him for a moment is enough. To the person with dementia, the person who is so close to him may symbolize someone from his life history. Who this is exactly is irrelevant. The verbal technique used is the technique of ambiguity (Feil 1992): “Isn’t that nice?” “Is it that bad?.” The person with dementia feels understood. Experiencing appreciation: contact opportunities should be sought in the physical and sensory experience. The caregiver needs to show respect, warmth, and understanding.

Experiencing Affirmation and Validation Although their sense of who they are is vague for people in the hidden Ego-experience, they do prove sensitive to an appeal to their identity, for example, by reminiscing together with the person with dementia with the aid of old photographs or familiar objects about positive events in his past. Awareness of the life history of the resident with dementia is therefore important.

4.1.2.7 Care in the Phase of Sunken Ego-Experience

Accepting Dependence and Control People in the phase of sunken Ego-experience were once thought to be in a vegetative stage. The care would therefore be limited to the body. In the integrated emotion-oriented care, the daily care is also used to nourish the person with dementia and provide him with pleasant sensations. People with high muscle tone and contractures are easier to help with principles from, e.g., the PDL approach and basal stimulation, and they respond well to relaxing massage. The person with dementia responds primarily to physical and sensory stimuli. These can be offered, for example, through bodily experiences like massage and warm bathing, sensory stimulation, aroma therapy, and music.

4.1.3 How Integrated Emotion-Oriented Care Can Influence Adaptation

In the adaptation-coping model, the seven adaptive tasks are considered as important aspects of cognitive, emotional, and social adaptation in dementia. Starting from the "coping" perspective, we examine for each of the adaptive tasks how they can cause behavior and mood problems or disruptions in the daily functioning of people with dementia. Subsequently, we describe how integrated emotion-oriented care attempts to prevent, reduce, or eliminate these disruptions and problems.

4.1.3.1 Integrated Emotion-Oriented Care and Cognitive Adaptation

Coping with the Own Invalidity

A dementia syndrome, as stated before, is characterized primarily by cognitive disabilities. Accepting and coping with these disabilities in daily life requires constant adaptation from the person with dementia.

Adaptation may take place, for example, by developing skills that compensate for the disabilities. Due to the presence of cognitive impairments and the ongoing deterioration, a general assumption is that people with dementia are able to adapt or, as Sacks (2012) puts it, "to reassemble their world," only to a very limited extent.

Various authors point out that the behavior of people with dementia proves that they find ways of coping with the consequences of their illness (Dröes 1991; Cotrell and Lein 1993; Clare 2009; Dirkse et al. 2011; de Werd et al. 2013). Dröes (1991) mentions four coping strategies that appear to be used with regard to "coping with the own invalidity": obsessive and compulsive behavior, taking the shape of, e.g., extreme neatness and the urge to walk; denial, as manifested in confabulation and the denial of cognitive disabilities; avoidance, which refers to avoiding test situations; and regression (reduction of interests and initiative, increased egocentricity, dependent behavior, and motor passivity) (Dröes 1991; Clare 2002, 2003; De Boer 2011; Steeman 2013).

According to Dröes, the regressive coping strategy in particular has negative side effects for the person with dementia and his environment. If taken to extremes, this coping strategy can be accompanied by insecurity, suspicion, disruptive behavior, and "excess disabilities" (this refers to the fact that the person with dementia exhibits more disability in his daily life function than one would expect on the basis of his abilities; Cohen 1986; Dröes 1991). She feels that activating and supporting these people may contribute to a reduction of these accompanying symptoms, partly because the person with dementia experiences which possibilities and skills he still has through activities and partly because he learns to trust people in his environment who will help out when necessary.

What does integrated emotion-oriented care do? Integrated emotion-oriented care offers support, in the context of the care objective "accepting dependence," with regard to the problems that elderly people with dementia can experience with coping with the disabilities that may come with old age and dementia.

In the different phases of Ego-experience, the following strategies are central:

1. Care "with hands behind your back"
2. Offering prothetic support and gradual taking over of actions
3. Building up trust in case of (total) taking over of actions, continuing to respect free choice
4. Offering physical and sensory stimuli

By always customizing the care to what is pleasant for the resident and what he is still able to do, the elderly person is validated in his individual being and possibilities.

Developing an Adequate Care Relationship with the Staff

In the nursing home, the resident with dementia depends on the nursing staff in terms of getting the required help and assistance. It is therefore important that an adequate care relationship with the staff is developed. One of the preconditions for this, from the perspective of the person with dementia, is to trust the caregivers. As a rule, this trust will develop if the elderly person regularly experiences that the caregivers sense what he can do himself and what he cannot and that they are willing to help him with the actions and activities he wants to be helped with and keep their distance when he chooses. Based on this trust, the person with dementia usually will not have a problem accepting the offered help. He feels respected in his autonomy and independence.

One of the problems, however, that elderly nursing home residents with dementia may have to face is the daily changing of the staff. This complicates the development of a trust relationship, especially for people who have trouble telling the different staff members apart. Two coping strategies that dementing elderly people seem to use to cope with this situation are regression and resistance (Dröes 1991; De Lange 2004). In this case, regression is characterized by a compliant, helpless, and passive attitude: to placate to their mind anonymous caregivers and to be ensured of care, the elderly person adopts a submissive and helpless attitude toward every caregiver. He exhibits so-called good patient behavior. One of the negative side effects of this strategy is the so-called acquired helplessness (Nelson and Farberow 1980). If the person with dementia fails to develop a sound care relationship with the staff, it can furthermore lead to depression (Flannery 2002; Miesen 2012). The nondevelopment of an adequate care relationship can also result in resistance in order to get some control over the situation. This can be expressed in, for example, agitated, aggressive, rebellious, and uncooperative behavior toward the staff. This is also referred to as bad patient behavior. This behavior should be viewed as an expression of dissatisfaction with the existing relationship with the staff.

What does integrated emotion-oriented care do? In the context of the care objective "experiencing control," integrated emotion-oriented care explicitly offers attention to the development of a sound care relationship between residents and caregivers. In the first three phases of Ego-experience, the following strategies are central:

1. Offering security, e.g., in the shape of a warm living environment, and developing and maintaining rituals
2. Offering structure by means of familiar faces, familiar rooms, and reference points on the ward
3. Inspiring trust by assigning the same caregiver to particular residents as much as possible (resident assignment) and by carrying out care actions and procedures along established lines

In all phases, the caregiver must delve into the life history of residents and try to empathize as much as possible with their experiences and perceptions, so that they can tune to the person more adequately in the care relationship.

The techniques used are derived from, among other approaches, reminiscence (talking with the resident about the past based on old photographs or objects) and validation (empathic communication): listening closely to the words the person uses, trying to verbalize unspoken needs that are expressed in behavior, mirroring actions and posture of the person with dementia, and going along in the movement rhythm of the person with dementia.

4.1.3.2 Integrated Emotion-Oriented Care and Emotional Adaptation

Maintaining an Emotional Balance

The changes that the dementia brings to the life of the elderly person, such as cognitive impairments, the forced move to the nursing home, and being separated from family and friends, can cause a considerable disruption of the emotional balance. Dröes (1991) mentions coping strategies that elderly people with dementia appear to be using to maintain control over the grief, anxiety, and uncertainty that come with these changes: overcompensation and counterphobic behavior, as expressed in agitated, aggressive, and hostile behavior; suppression, e.g., in wandering behavior (during the day and during the night) and manic behavior; depression with projective traits (whining, agitated, accusing); and depression with regressive traits (withdrawing, apathetic and excessively dependent behavior). If there is not enough activity and distraction for the person with dementia, the "suppression" strategy can easily lead to (night time) restlessness. Accompanying symptoms of the "regressive and projective depression," respectively, are sad and aggressive behavior. Important determinants for maintaining an emotional balance are having fun regularly, being able to freely express positive and negative feelings, and a sense of control (Dröes 1991).

The general principle is validation of feelings of anxiety, happiness, sadness, and anger by naming them, so that residents may feel understood. This method is taken from the validation approach. In some cases, caregivers also help to control or guide emotions, e.g., by using humor, putting things in perspective or using confrontation, or leaving the resident alone.

To have the person with dementia experience he is appreciated, the following strategies are among those used in the successive phases of Ego-experience: (1) appeal to personal qualities, (2) talk about life themes and losses individually and in groups, (3) show respect and warmth, and (4) nourish the resident in the daily care and have him experience pleasant sensations. In all phases of dementia, the staff examines what the resident enjoys, and this is taken into account in the care. Examples are playing specific music, offering nice foods, and letting them smell pleasant fragrances. This method is based on the principles of sensory activation/snoezelen.

What does integrated emotion-oriented care do? The attention that integrated emotion-oriented care pays to the affective functioning of residents with dementia may be expected to actually help them to maintain an emotional balance with less agitated, restless, dependent, depressive, and anxious behavior.

Maintaining a Positive Self-Image

Illnesses that are accompanied by permanent functional disabilities require an adjustment of the self-image that takes into account the invalidity. According to Van der Wulp (1986), this is a precondition for experiencing continuity in past, present, and future. If there is no revision of the self-image, the patient may experience this as a conflict with continuity and a disruption of his identity. This, obviously, has negative consequences for the satisfaction with the current life situation and on mood in general.

Based on this line of reasoning, Dröes (1991) indicates that it is not inconceivable that some people with dementia, i.e., those who withdraw frequently into the past and deny the present, do this because they have a problem with their self-image, which has been affected by the consequences of their illness. But perhaps other behaviors can also be explained from this perspective. She names five coping strategies that people with dementia appear to use to maintain an acceptable self-image: denial, as manifested in confabulation and living in the (active) past in one's mind; avoidance (avoiding situations where one is confronted with one's inability); projection, as exhibited in paranoid delusions; withdrawing into one's own phantasy world, as manifested in, e.g., positive delusions; and depression, as a problem-oriented strategy to obtain attention and validation from others in the environment. If these strategies do not lead to the desired result, the balance may yet be disrupted, and the person with dementia may fall into a real depression. On the other hand, reduction of the coping behaviors mentioned (confabulation, living in the past, avoiding behavior, delusions, and depressive behavior) and an increase of satisfaction with the current situation indicate acceptance and adjustment of the self-image.

According to Dröes (1991), the regular experience of success (experiencing what one is still able to do) and validation of the sense of identity are important conditions for maintaining a positive self-image.

What does integrated emotion-oriented care do? In the context of the care objective "experiencing validation," integrated emotion-oriented care attempts to stimulate the sense of self-worth and in this way have a positive influence on the self-image of the person with dementia.

In the first three phases of Ego-experience, the following strategies are used: (1) Approaching the person with dementia in a "normal" way, by accepting what he is and not correcting or confronting him (all the time), only supporting him when necessary with memory facts or words; (2) Validating the person with dementia, if this is not confronting or asking too much of him, in his (current) identity by fitting in satisfactory activities from the past in his current life in the nursing home whenever possible; (3) Appealing to his identity by reminiscing together with the person with dementia, for example, with old photographs or familiar objects, about positive events in his past

In the final phase of Ego-experience, the method is limited to having the person with dementia experience pleasant sensations, because it is assumed that he no longer has a sense of identity.

The techniques used in the different phases are derived from the reality orientation approach, the validation approach, reminiscence, sensory stimulation, and PDL. The attention that integrated emotion-oriented care pays to the identity feelings of the person with dementia (in the past and the present) and the actions that are undertaken to have the person with dementia experience success in his daily functioning are expected to contribute to a modified self-image and preservation of the sense of self-worth on the one hand. On the other hand, they are expected to lead to the person with dementia having to attempt less actively to keep his self-image positive. In terms of behavior and mood, this means that we expect the person with dementia will exhibit less of the coping behaviors mentioned (confabulation, living in the past, delusions, and depressive behavior) and will be less dissatisfied with his current situation.

Preparing for an Uncertain Future

The negative prognosis of dementia and the progressiveness of the disease with its increasing disabilities make the future for people with dementia extremely uncertain: it is unclear to what extent and how quickly they will become dependent on others, whether or not these others are willing and able to take on this care, whether or not they can stay in their own home, etc. This uncertainty can furthermore be compounded by fear of the approaching death. In this context also, withdrawing into the past and denial appear to be frequently used strategies to maintain a balance (Dröes 1991). There is no confrontation with the present and the future. If the person with dementia does confront them, it is possible he will gradually accept the loss. If this takes place at an early stage, the necessary arrangements can be made, in consultation with the partner or family, for the time when the person enters a more serious stage and is no longer able to make his own decisions. However, experiencing one's own deterioration and the awareness that one suffers from a progressive disease can also lead to the person losing heart, because he no longer feels his life has meaning. Verwoerdt (Dröes 1991) considers refusing to eat and preferring to lie down signals that the person is giving up.

The support people experience from their faith or from others in their immediate environment may contribute to their being less anxious and more able to accept the losses they go through.

What does integrated emotion-oriented care do? Although "preparing for an uncertain future" is not a separate care objective within integrated emotion-oriented care, attention is given to "the spiritual experience and signification" of residents.

Integrated emotion-oriented care offers support with regard to accepting the losses that people with dementia go through and in preparing for the end of life.To help accept the losses, caregivers discuss with the residents, especially in the first two phases of Ego-experience, how he experiences his current situation and show understanding and compassion when the resident is anxious or no longer sees a meaning to life.

To inventory which activities or religious beliefs the resident derives meaning from, the caregivers approach the resident himself and his family. Apart from reading or listening to music, integrated emotion-oriented care applies activities like going to church, attending bible study group, or singing together, to give the residents support and new energy. Preserving fixed habits, such as praying before meals and sleep, has the same function. This method of integrated emotion-oriented care is expected to have a positive effect on the acceptance of the losses the person goes through. It therefore is expected to lead to a reduction of anxiety and feelings of insecurity. This might reduce the necessity to withdraw into the past and deny the current situation, and the chance that the person gives up in an early stage, because he no longer sees any purpose to his life, may become smaller.

4.1.3.3 Integrated Emotion-Oriented Care and Social Adaptation

Coping with the Nursing Home Environment

The forced move to a nursing home brings about a number of drastic changes in the life of the elderly person with dementia: he loses his familiar surroundings and a large part of his freedom of movement and privacy; the role of nursing home resident requires adaptation to the nursing home values, norms, and rules; and the person with dementia is expected to undergo various treatments, such as physiotherapy, movement therapy, and/or activity therapy.

Elderly people appear to use different coping strategies to handle the stress that the institutionalization may cause (Dröes 1991): denial, as shown in confabulation, living in the past, and convincing oneself that one is only visiting the nursing home; suppression, identified by euphoric and relieved behavior; command and control of the new environment, as shown by expectant or explorative behavior and active participation in organized activities; and expression of feelings (rebellious, agitated, and aggressive behavior).

The closed world of the nursing home furthermore carries the risk that residents will hospitalize with time. Hospitalization can be understood as a type of regressive coping with an environment one (believes one) cannot influence. The person submits to the norms and rules, the organization, and the representatives of this organization (staff). This regression enhances the dementia syndrome and is characterized by, among other things, passivity, dependent and subservient behavior, apathy, and socially isolated behavior. By creating a domestic environment, regularly organizing recreational/creative activities and emphasizing the resident role and the say of the person with dementia, the adjustment in the nursing home can be furthered, and hospitalization phenomena may perhaps be prevented to some extent.

What does integrated emotion-oriented care do? In the context of the care objectives "experiencing control, appreciation, and validation" and the "social experience" field, integrated emotion-oriented care also offers the elderly person with dementia support in coping with the nursing home environment. The underlying reasoning is that residents will feel more at home in the nursing home if they feel safe, if their values and norms are respected and they have satisfying activities and contacts that link up with their own experiences and perceptions, and that this simultaneously counters, or prevents, hospitalization phenomena.

In the first three phases of Ego-experience, the following strategies are used to accomplish the mentioned objectives: (1) activating residents to take on social roles and stimulating them to participate in domestic and recreational/creative activities, helping them preserve old habits and rhythms by adjusting the care, helping them develop new habits in the new living environment, and making sure there are sufficient reference points; (2) discussing feelings regarding losses (e.g., of the own home) and stimulating them to participate in satisfying recreational/creative activities which are tuned to the abilities of residents and their experiences/perceptions; and (3) offering warmth and showing understanding and respect in direct contacts with a resident. People in the phase of sunken Ego-experience are scarcely aware of their environment. Still, people who are in this phase sometimes are placed in the living room lying on bed. Sometimes their rooms are given a warm and vivid atmosphere with mobiles, pictures, dolls, and so on.

The methods described are derived in part from ideas regarding normalization of the living environment and in part from the validation approach (discussing life themes, social roles) and the reality orientation approach (reading the paper, structuring activities, reference points).

The resident and his family are asked to supply the information needed to determine which activities are experienced as significant by the residents.

In integrated emotion-oriented care, the nursing assistant is assigned an important role as the person who creates the atmosphere in the nursing home. To further the homy atmosphere, she will, e.g., wash the dishes in the living room, iron, make coffee, or sow on buttons, and she will actively involve residents by asking them to help drying the dishes, folding the laundry, pouring the coffee, or distributing biscuits. Nursing assistants also guide relaxation activities, such as playing cards and singing.

In view of the individualized methods used in integrated emotion-oriented care to help familiarize dementing people in the nursing home with their new living environment and create a home there, one can expect that they will initiate activities more frequently and will participate in organized activities in the nursing home. Furthermore, one can expect that manifestations of hospitalization, such as passivity, dependent and subservient behavior, apathy, and socially isolated behavior, will be reduced or prevented.

Developing and Maintaining Social Relationships

In the long run, suffering from dementia unavoidably brings changes to the social life. Existing social contacts change, fade, or are lost. Communication breaks down. Not only because the person with dementia becomes cognitively impaired, which hinders the maintenance of relationships, but also because friends and acquaintances often don't know how to deal with the (changed) person with dementia. The move to the nursing home furthermore implies a physical separation from family, friends, and acquaintances. To prevent isolation after admittance to the nursing home, it is important that the person with dementia makes new contacts. Elias indicates that loneliness is partly related to the significance that people have to others. Important preventative aspects of loneliness are participating in activities and feeling that one means something to others (Linnemann et al. 1990). Behaviors that indicate that the person with dementia tries to build up a new social network include active participation in social activities inside and outside the nursing home and actively functioning in different social roles, such as conversation partner, kitchen help, table setter, coffee pourer, table companion, etc. (Hanson et al. 1986; Dröes 1991). In actual reality, however, we see a lot of social passivity (sleeping, sitting, little initiative, and social contact) among nursing home residents with dementia (Hiatt 1987). According to Dröes (1991), this social passivity can perhaps be partly explained as regressive coping (withdrawing) with the socially depriving environment (institutional rules, patient role, high social density). The person with dementia runs the risk, however, of becoming lonely and isolated within the nursing home.

What does integrated emotion-oriented care do? In the context of the care objective "experiencing connectedness," integrated emotion-oriented care responds to the need of the resident with dementia for social contact. This response uses not only information about their current social functioning but also about how they functioned in the past. Did a person like to be by himself before, or was he more of a sociable person? What is that like now? Is it easy for the resident to make contact with other residents and staff? Does the resident like to sit in a circle or does he prefer the isolation of his own little corner? This information may be helpful to find, for example, a suitable place in the living room, the potential new friends, the offer of group activities, the role of the resident in those activities, etc. Proposals made to the person with dementia to participate in activities are aimed at continuing old and/or developing new contacts. For example, the resident can be stimulated to fulfill particular roles (such as coffee pourer, card playing partner, dance partner, member of the singing club) in order to expand his contacts. This method is partly based on the validation approach. Furthermore, in the successive phases of Ego-experience, the following strategies are used in the personal life to make residents experience a sense of connectedness:

- Phase 1: showing understanding for the feelings (tension, anger, anxiety) that the resident experiences in his situation, radiating security, interest, respect, and closeness
- Phase 2: responding to social initiatives from residents, helping to keep the conversation on track, and empathic communication
- Phase 3: offering activities that will invite the resident to make contact with his environment (including music and movement), mirroring the resident's posture and movement, and eye contact help to tune to his feelings and invite him to share feelings
- Phase 4: contact by means of physical and sensory stimuli

In view of the method of integrated emotion-oriented care to preserve contact with the residents and give them the opportunity to fulfill social roles – whenever possible – we may expect that residents will withdraw (regressive coping) less frequently after institutionalization in the nursing home and that they will make more contact with fellow residents and caregivers.

4.1.4 Finally

In this chapter we have seen how integrated emotion-oriented care provides guidance and support to people with dementia in different areas of adaptation. We described which strategies integrated emotion-oriented care implies in different stages or phases of Ego-experience in dementia. We have tried to make clear how you can recognize as a care professional when someone has problems with the cognitive, emotional, and/or social adaptation and how you can support the person with dementia using the integrated emotion-oriented care approach. People with dementia will therefore experience less stress, and there will be fewer behavioral and mood disturbances.

4.2 Section B: Implementing Psychosocial Interventions

Linda Wolter

4.2.1 Introduction

Psychosocial intervention (PSI) is defined as “A non-pharmacologic intervention intended to alter a person’s environment or reaction to lessen the impact of a mental disorder” (McGraw-Hill 2002). The intent of PSI is to maintain and improve the quality of life for the residents. For residents with dementia, the uses of psychosocial interventions address both the environment and the residents’ perceptions and reactions (Kasl-Godley and Gatz 2000). Psychosocial interventions are grounded in many different theories; despite the fact that psych-dynamic theories have much in common, ego psychology puts relatively more emphasis on how the ego successfully copes with conflict and adapts to the environment (Wolitzky 1995). Dementia results in weakened ego functioning diminished mastery over the environment and increased dependency (Kasl-Godley et al. 2000). Psychosocial interventions assist the residents in developing new coping and adaption skills.

Watts et al. (2013) state that psychosocial interventions intended to help people maintain a good quality of life. Interventions include:

- Adjustment to a dementia diagnosis
- Communication
- Stress, anxiety, and depression
- Memory and cognitive functioning
- Living independently, quality of life
- Support for partners and families

As mentioned earlier in this chapter, Finnema et al. (2000) stated that building trust with the residents and nursing staff’s attunement to their moods and behaviors are key to building trust and considered the first step in successfully implementing psychosocial intervention with dementia residents. For trust to be established, it is important for the nursing staff to understand how trust initially is experienced and internalized.

4.2.2 Building Trust

McLeod (2013) states Erick Erickson’s life-span developmental theory speaks to psychosocial tasks each individual must resolve. According to Erickson, the first stage of development, trust versus mistrust, occurs at birth to age three. When the infant experiences hunger, pain, fear, etc., they communicate their distress by crying. It is through the caregiver’s attunement and timely response that the infant’s distress and discomfort are alleviated and trust is established. In working and caring for dementia residents, attunement, timely responsiveness, and consistency create the foundation for building trust. When the facility or nursing home staff fails to provide an attuned, timely, and consistent environment, residents will display challenging behaviors, such as agitation and aggressiveness, or become withdrawn and depressed. Building trust and secure environment with residents is both the nursing staff's and facilities' responsibility.

Sutor et al. (2001) noted that dementia residents who referred from long-term care facilities to the Mayo clinic psychiatric wards were docile and pleasant when they were on the ward but exhibited challenging behaviors when they returned to their care facilities. Smith states, "What we realized then is that the problems didn't reside in the residents but in the setting". Environmental settings influence both moods and behaviors. Research has found that higher nursing home staffing leads to higher quality of care (Harrington et al. 2000). The level of individual care should be considered when scheduling of care staff and patience ratio. In addition, training for care providers will assist staff ability to provide consistency when implementing psychosocial interventions. With dementia residents, timely response to requests for assistance or addressing physical discomfort not only builds trust but also may limit the residents' agitation and aggressive behaviors. In addition, consistency among multiple care providers will enhance and maintain a sense of trust and predictability for the residents.

It is with the establishment of a secure environment and consistent staff responses the focus for implementing psychosocial intervention shifts from the residence's external world to their internal world and through reminiscence and self-reflection, thus enhancing the residents' dignity and sense of worth. "Given the considerable impact the social environment has on the personal dignity of people with mild to moderate dementia, it is important in caregiving not to confine attention to health-related or even any individual aspects alone, but also to take interpersonal aspects into consideration" (Gennip et al. 2016).

4.2.3 Enhancing Integrity Through Reminisces and Self-Reflection

Erickson's (1959) eighth stage in the life-span is ego integrity versus despair. It is during this time that the individual will contemplate their accomplishments and are able to develop integrity if they view themselves as leading a successful life (McLeod et al. 2013). Characteristics of integrity include honesty, reliability, and honor. It is through reflection and reminisces the residents will examine their past. Reflections as a psychosocial intervention include careful thoughts about one's behavior and values. Implementing this intervention is best done through verbal or written communication. Reflection of meaning refers to the deeply held thoughts and meanings underlying life experiences. Care providers assist reflection by encouraging the residents through questions about what they thought and how they felt during the experiences. In some cases, the care provider may hear different residents reflect on similar life experiences, marriage, parenthood, and careers and find the same event can have a different meaning to the different individuals (Hill 2009). For residents in nursing homes, self- reflections and reminiscent interventions done individually provide a safe and supportive environment to look inward and remember.

Activities done in group settings, be it other family members, residents, or community visitors, provide both social and psycho skill building. According to Kennard (2016), reminisce activities vary in mediums and include:

- Visually: photographs and slides. Painting pictures, looking at objects of autobiographical meaning
- Music: using familiar tunes from the radio, CDs, or making music using various instruments
- Smell or taste: using smell kits, different foods
- Tactile: touching objects, feeling textures, painting, and pottery

Reminisce activities such as mentioned above all aid in and enhance social skills of dementia residents in nursing homes. Group work or group activities have always been seen as powerful interventions in working with people who feel isolated, lonely, and fearful. These emotions are common among dementia residents in nursing homes. In addition to social skills building, reminisce groups have shown other health benefits such as decreasing depression and pain, improving mood, decreasing stress, and calming challenging behaviors (Cohen-Mansfield et al. 2005).

Traditional barriers to providing psychosocial groups to the aging population such as location, accessibility, and transportation are nonexistent for nursing home residents. Many nursing home residents establish new friendships and relationships with others. The relationships that exist among nursing home residents are potent and, however, should not be viewed as the culmination for social interaction. The "social" aspect of psychosocial interventions is achieved through groups. Building a broader perspective of the residents' world should include diversity that extends beyond the facility's staff and other residents.

4.2.4 Multigenerational Programs

As important as the activities are, so too is the group membership. One medium of intervention that has shown consistent success for older adults is intergenerational programs. Intergenerational programs began in 1963 as part of the war on poverty in the United States. Intergenerational programs are social vehicles that offer younger and older generations the opportunities to interact and become engaged in issues concerning our society (Generations United 2002). Benefits for older adults include enhanced socialization, stimulated learning, increased emotional support, and improved health.

Carlson et al. (2000) found in their study that older adults want to remain productive and engaged in the community. A way to prevent isolation in their later years is to increase interaction with children and youth through intergenerational programs. Learning is life-long experience. One study showed that older adult quality of life is enhanced through learning and sharing what they know with others. Glass (2003) found older adults show an increase in emotional support and improved health and through structured and social activities. In another study, adults with dementia or other cognitive impairments experience more positive effect during interactions with children than they did during non-intergenerational activities (Jarrott and Bruno 2003).

Galbraith et al. (2015) found in their literature review of 27 research projects looking at intergenerational programs for dementia residents that music, art-based, and narrative programs were most common in intergenerational programs. Outcomes include effects on perceptions of aging and dementia, behavior, mood, engagement, and sense of self. Activities that were meaningful for participants and supported shared opportunities for relationship building and growth saw outcomes that are more positive.

Creating multigenerational programming is relatively easy. Extending invitations to local elementary, high schools, and universities can provide a rich pool of younger people who can benefit from one-on-one time with older adults. For residents in nursing homes, children and adolescents may be viewed a “breath of fresh air” and provide a sense of happiness that comes from giving something to another.

4.2.5 Summary

In this section, we have discussed psychosocial interventions. How nursing home staff provides attunement, knowledge, and consistent and timely responses to residents is significant to building a trusting, safe environment. Psychosocial interventions for dementia residents, such as sensory stimulation and reminiscence activities, are fundamental to long-term health and well-being. In addition, the mediums, individual, group, or multi-generational in which reflective and reminisce activities occur, are crucial to residents’ ability to adapt and grow in new environments.

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