Abstract: As humans, we have a sense of self, and at best, we are proud of our abilities and feel respected by other persons. Persons with dementia have been regarded losing their self. Quantitative research has shown that this is true, while qualitative research has shown that parts of self are severely affected while other parts remain even among persons with advanced dementia. These persons sometimes keep feeling “still the same” as before getting dementia. Their memory deficits help as does support from other persons. The theory of three aspects of self by the psychologists Rom Harré and Steven Sabat are presented, that is, the feeling that we are, who we are, and who we are together with other persons. Based on empirical research, suggestions will be given about how by promoting experiences of at-homeness, dignity, and being oneself related to others we can help persons with advanced dementia experience themselves as valuable persons.

Keywords: advanced dementia; anosognosia; confirmation; dignity; self
INTRODUCTION

As human beings, we need to know that we are and who we are. We need to be proud of our abilities and feel respected by other persons. These experiences can often be hard to achieve for persons with dementia, partly due to symptoms of dementia and to a great extent due to other persons’ reactions. There are reports that persons with dementia lose their self and also that it is at least partly preserved. A systematic review revealed that studies performed with quantitative methods generally described that among persons with dementia self was affected, while qualitative studies tended to find that self was at least partly preserved (1). These results are in line with Sabat (2) who argued that self should be investigated by sensitive methods.

The Latin root of the term dementia means to be out of one’s mind (3), and dementia has been described as leading to affected persons losing their self and becoming non-persons (4). Thus, it seems reasonable that the term dementia has been subject to criticism, and the American Psychiatric Association has replaced it with the phrase “major neurocognitive disorder” in the Diagnostic and Statistical Manual (DSM-5) (5). Sabat (6) argues that we should not reduce persons to brains but see the persons behind the dysfunctional symptoms and remember our shared humanity. Those living with dementia are semiotic persons, that is, their behavior is driven by meaning, as they, for example, have the capacity to show shame and pride and to feel concern for other persons’ well-being (7). They are also relational beings and their behavior is an effect of neuropathology, their reaction to these effects, others’ ways of treating them and their reaction to that treatment (8). Healthy persons often use negative stereotyping of persons with dementia which may lead to these persons themselves using self-stereotyping (9).

There are several types of dementia diseases, with Alzheimer’s disease as the most common type. The disease progresses from a mild stage, via a moderate stage, to an advanced stage in which affected persons are dependent on others in most situations (10). In the literature about care, the term “dementia” is sometimes used and sometimes the type of dementia is identified. Here, I use the term “dementia” when I refer to literature using the terms “Alzheimer’s disease” or dementia without further specification.

SYMPTOMS OF DEMENTIA

The cognitive symptoms of dementia can be described as four As, namely amnesia (impaired memory), apraxia (impaired ability to organize sequences of movements in space), agnosia (impaired perception), and aphasia (impaired language ability) (11). Amnesia affects first the short-term memory and later also the long-term memory. A decreasing autobiographic memory (incident memory about specific personal events including context and personal semantic memory such as names of friends) affects sense of self (12). In interviews, persons with moderate dementia can often provide short accounts of their experiences. They may narrate fragments of their life story: childhood, education, family life and professional life. Several persons describe specific events such as leaving home to go to school (13, 14) and narrate thoughts about their future life, that is, about possible selves (15). Apraxia causes
problems with performing everyday tasks like, dressing, eating, grooming, and walking. Agnosia causes difficulties in recognizing, for example, colors, persons, objects, odors, shapes, and sounds. Aphasia leads to difficulties with both speaking and comprehending speech (16). Persons with dementia use circumlocutions and paraphrases as they forget words, and they need prolonged time to understand the meaning of what has been said, and to formulate answers (17). They also often can compensate by using extralinguistic means such as gestures and tone (18).

**SELFHOOD**

There is no consensus about the meaning of the concepts of identity, person, personhood, self, and selfhood. The terms are often used interchangeably although there are many different conceptualizations (19–20). Studies on the sense of self in persons with dementia have used various concepts or failed to describe the concepts used. Here, I use the term “self” also when I refer to authors who use the terms “identity” or “personhood”. Thus, I use these terms as interchangeable.

The psychologists Sabat and Harré have together (21), separately (17, 22), and together with other researchers (23) published about a social constructionist theory of selfhood in persons with dementia.

The embodied, material human being they label “person,” and the linguistic expressions we use to refer to ourselves they label “self.” Selfhood is expressed both as speech and behavior in public discourse. Sabat and Harré describe self as tripartite: Self 1, Self 2 and Self 3. Self 1 (the self of personal identity) expresses our embodied experience of being singular continuous persons located in space, time and in a local moral order. We experience this aspect of selfhood in that each of us has one single point of view of the world, that is, our continuous experiences of events that form the narrative of our lives. Through the use of first-person singular pronouns, we take responsibility for our actions, feelings, and experiences as being our own and tell autobiographical stories. We manifest Self 1 when we speak in first-person indexicals (“I,” “me,” “mine,” “my,” “our”) or indicate Self 1 nonverbally for example by pointing to ourselves (21, 24). Self 1 is a necessary condition to be able to reflect on our personal attributes (Self 2) and exhibit them in appropriate social situations (Self 3).

Self 2 is comprised of how we perceive our physical and mental attributes such as eye pigmentation, height and weight, educational achievements, political and religious convictions, sense of humor, and vocational pursuits. We have beliefs about our attributes, such as that they are adequate or outdated and also emotions related to them such as pride or disdain. Some Self 2 attributes have long histories such as being a daughter, while some may be more recent such as being diagnosed with dementia. Self 2 can be restricted and unrestricted. The restricted Self 2 is about how we perceive ourselves to be in the moment, while the unrestricted Self 2 includes both how we are in the present, how we were in the past and may develop in the future, that is, our relatively constant, temporary or ever-changing attributes, such as traits, skills, and our beliefs regarding these attributes. We manifest multiple Selves 2 (22).

As persons with advanced dementia usually remember past attributes better than recent ones, they may feel proud of already lost attributes (25). For persons
with dementia, new Self 2 attributes include deficits connected to the neuropathology of the disease (24) and results of their attempts to adapt to the disease (26).

Self 3 (social personae) is a complex concept, in that it includes the perspectives of both the display and the perceiver. It is the display of Selves 1 and 2 to other persons. How we display Self 3, depends on the situation, on how other persons position us and how we position ourselves to them through actions or inner dialogues (23, 27–28). Persons with dementia may lose their sense of self-worth and feel depersonalized, depressed, and angry when healthy persons behave in manners that can be classified as “malignant positioning” (28–30). Previous research has described both the negative positioning of persons with dementia (27) and the understanding and support that they sometimes receive (13). It is obvious that support from other persons is important for preserving a sense of self (20, 30). If others focus on dysfunctional Self 2 attributes of persons with dementia, their Self 3 (social persona) is restricted to “the patient” (28). If other persons focus on remaining healthy Self 2 attributes, it is possible for the afflicted persons to construct worthy Self 3 that makes them experience pride and satisfaction. (24). We manifest multiple Selves 3 that are constantly reconstructed in the interplay among persons (22).

Studies based on the Harré–Sabat theory of selfhood have shown that among persons with mild to moderate dementia, Self 1 was not affected during the course of dementia, whereas Selves 2 and 3 were (13–15). A few studies using that theory concern persons with advanced dementia (e.g., 24, 31–33). Studies that do not use the Harré–Sabat theory have found that some aspects of sense of self were preserved while other aspects were reduced among persons with advanced dementia (e.g., 34–37). Kontos (38) argued that selfhood is an embodied dimension of human existence persists even with advanced dementia. These persons have several preserved abilities despite losses of cognitive functions, for example being able to assess their own internal state of being such as feeling cold (39) and experiencing pain (40). Here, I use the term “advanced dementia” to describe information in articles about persons with moderate to advanced dementia as well as with advanced dementia.

PERSONS WITH ADVANCED DEMENTIA

Having advanced dementia involves many strains. Neighboring persons, carers, and everyone who meets these persons need to provide them support.

Awareness and lucidity

Although persons with advanced dementia are often described as having lost their self (4), their sensory and perceptual awareness has been found retained (41). These persons show distinct individual reactions to particular kinds of stimuli, and they, for example, differentiate between pleasant and unpleasant experiences, or various pieces of music (42–44). If the self is lost, it is difficult to understand the meaning of moments of lucidity (cognitive fluctuations) that have been identified when persons with advanced dementia that seem “not there” suddenly show
that they understand, remember, and care (42, 45). It was evident that lucidity during conversations with a woman with advanced dementia occurred when her communication partner supported her by showing that he shared her expressed view, repeating and reformulating her words, using positive words and statements, helping by suggesting words and starting, completing and ending sentences and not emphasizing errors in her speech (46).

**Suffering**

Living with advanced dementia includes several negative experiences. When writing about suffering among persons with advanced dementia, several researchers write about experiences of pain and bodily distress (47). Few writers have explicitly focused on the other various experiences of suffering in persons with advanced dementia although carers often feel that these persons indeed suffer.

Eriksson (48) described three categories of suffering: “suffering of life” (for example grief due to the death of a friend, or feeling abandoned when friends do not pay visits to the nursing home), “suffering of illness” (effects of having dementia such as not feeling at home, having problems communicating), and “suffering of caring” (distress caused by received care). An example of “suffering of illness” is that several persons with advanced dementia have neuropsychiatric symptoms such as apathy, depression, irritability, agitation, sometimes delusions, hallucinations, and sleeping disorders (49). Examples of “suffering of care” are reports that carers have been observed treating persons with advanced dementia as object (50) which reasonably cause them suffering. Living with advanced dementia can also be experienced as a relative well-being (29) mainly through carers’ compensating for problems related to the disease (51).

**Anosognosia**

Many persons with advanced dementia have been reported to suffer from explicit or implicit “mnemonic anosognosia” anosognosia that makes them seem unaware of deficits caused by neurodegeneration although they may demonstrate implicit awareness (52–54). Their memory deficits can make their sense of self become a “petrified self,” that is frozen in time and sometimes reflects the features that were accurate in early adulthood and perhaps even in childhood. Thus, memory impairments hinder the persons to update information about self. Sometimes, they may register impairment but they cannot integrate the information into a coherent picture of their situation. This may lead to stable but inaccurate evaluation of experiences and actions (54).

**Moments of homecoming**

Feeling at home is a fundamental aspect of human existence (55), and it is important for our sense of self (56). Thus, losing one’s home is losing one’s self. To feel at home through the life cycle has been described as feeling related to oneself, significant activities, significant others, significant places, significant things, and to feeling a sense of transcendence (57). Persons with advanced dementia often appear to feel homeless, they may walk around, asking where they are and
searching for their home. They have problems feeling at home both in their former homes and in their new places of residence (58). The understanding of how important the experience of at-homeness is for our sense of self and well-being has led to an endeavor to create care environments where persons with advanced dementia can feel at home. However, although carers try to furnish the rooms as homely as possible it is often hard to document positive effect on the persons’ daily life (59). Observation of nursing home residents with advanced dementia showed that they alternated between expressing feeling at home (at-homeness) and not feeling at home (homelessness) both verbally and nonverbally. They showed often short lived moments of homecoming that were characterized by “being released from burdens and demands (e.g., not being required to make choices), being united with actions (e.g., being helped to use previously familiar routines when getting dressed), and being reached by language (e.g., being spoken to with familiar words)” (60). One woman seemed to live and feel at home in two worlds simultaneously, that is, she interpreted some things that happened at present as something that happened earlier in her life (61). In her “remembered-world,” she took care of her small children and had coffee with her friends and expressed astonishment about the fact that some nice and friendly persons entered her room, made her bed and invited her to dinner. In her “care home-world,” she could tell her carers about her grandchild having taken an exam.

**Communication**

Persons with advanced dementia may show some retained abilities to communicate, they for example sometimes are using politeness when communicating (62). Their communication difficulties are, however, more often acknowledged. They can show lack of interactional synchrony such as integrating verbal and nonverbal communicative cues to a whole and synchronize their actions with their communication partners by adequate turn-taking. First the carer talks, then the person answers, then the carer answers, then the person shifts theme etc. The lack of synchrony makes behavior chaotic and fragmented. The persons’ sensitivity to representative meaning and less to affective meaning is reduced due to decreased arousal and attentiveness. They often send vague undifferentiated verbal and nonverbal cues that are difficult to interpret for the communication partner. They also show problems interpreting the communication partners’ cues and they need prolonged time for responding to their partner. They may use short sentences but more often single words or even react with primitive reflexes (63). Communication partners sometimes have to impute or attribute meaning to the vague cues, that is, they make guesses that are based on their previous experiences with the person in question and with other similar persons or on empathy or intuition (50, 64). Sometimes, the communication can depend on the communication partners imitating each other (65). When I tried to help a person with advanced dementia to eat and the person did not seem to understand, I demonstrated what I meant by opening my own mouth, chewing and swallowing. I ate an air meal. Suddenly, the person seemed to understand and started eating (The author’s experience). Both imputation of meaning to vague cues and imitation can help the persons feel like partners being answered, that is strengthening the Self 3.

At the end state, persons with advanced dementia may become mute (66). Hughes (67) argues that there are other means to understand persons with
dementia than understanding the words they use. It is about sharing a form of life, it is about understanding the context, and feeling what the persons express. This is like using affect attunement, that is, the carer tuning into the persons’ affective state to be able to help them to reduce negative affect and increase positive affect (68, 69). In this way, communion between the partners is created. According to Stern (70), the sense of self starts with the parent and infant being in communion, that is, participating in and sharing emotions and vitality effects that, for example, are expressed through intensity and rhythm. Later, the sense of self gradually develops through interaction with others throughout one’s history to also include cognitive dimensions. As their cognitive abilities decrease, persons with advanced dementia increasingly need to be in communion with carers to preserve their vulnerable self. Söderlund et al. (71) reported positive results from using the Feil’s validation method during one-to-one conversations with persons with advanced dementia. The focus was not the facts about what was expressed but rather the feelings behind what the persons tried to talk about and the aim was to treat them as adults and increase their feelings of self-worth and well-being. Eggers et al. (72) described two somewhat different ways of interpreting the communicative cues of persons with advanced dementia, partly by establishing communion with them through affect attunement and partly by putting various fragments together until a picture of the meaning of utterances and behavior appeared. This was like completing a puzzle.

AGENCY AND COMMUNION

Agency and communion have been described as fundamental modalities in human beings’ lives (73). Communion is the urge to be connected and unified with others. The positive themes of communion are love/friendship, dialogue, caring/help, and unity/togetherness, whereas the negative themes are separation, rejection, disillusionment about people, and another’s misfortune (74) Agency implies a quest for autonomy, self-realization, and separation from other people. The positive themes of agency are self-mastery, status/victory, achievement/responsibility, and power/impact, and the negative themes are, failure/weakness, losing face, ignorance, and conflict (75). For a positive sense of self, we need agency (individuality) and communion (togetherness). Experiences of agency and communion have been assessed among persons with dementia (76). Although there are no clear-cut borders between the modalities, it seems as communion is more relevant for Self 1 and Self 3 and agency for Self 2.

Strengthening Self 1 communion

Being treated and even feeling as a non-person reasonably means suffering. Therefore, it is important to help persons feel as persons with a sense of self. Research has shown that the Self 1 is preserved among persons with advanced dementia. Even when they almost entirely answer “yes” or “no” to questions, they still show that they can experience themselves as “I” (32, 60). Still it seems reasonable to suggest that we can help persons preserve their feeling of being an I by making them feel that they are seen and listened to, that is that they are. This kind
of behavior has often been labeled confirming actions and seems a type of communion.

The concept of confirmation is based on Martin Buber’s philosophy and is described by Cissna and Sieburg (77, p. 254–260) as the process through which we endorse others by showing them recognition, acknowledgement and acceptance of their self-definition. Thereby they get help forming and maintaining human relationship. Cissna and Sieburg emphasize that confirmation includes four key elements: (i) The element of existence (the individual sees self as existing). (ii) The element of relating (the individual sees self as being-in-relation with others). (iii) The element of significance, or worth. (iv) The element of validity of experience. Observations at a small group living for persons with advanced dementia revealed that staff confirmed persons by accepting the ways they spoke and acted by making them feel accepted and allowed to be just as they were. A person who thought the ward is a church was not corrected as long as he appeared to feel good. Another person who found it meaningful to carry things around was allowed to do that as long as no one else was disturbed (78). It seems reasonable that confirmation could be seen as strengthening persons’ Self 1.

**Strengthening Self 2 agency**

Experiences of using motoric and other abilities can be understood as part of agency. Because Self 2 concerns persons’ perceptions of their abilities, it seems logical that there is a need that they both get opportunities to use their abilities and also get help to remember how they previously used their abilities. They most easily remember what happened during their childhood (54) and often express they are proud of these memories. In articles about needs of persons with advanced dementia, agency is mentioned (51, 78). To my knowledge, there are few studies presented about agency among persons with advanced dementia. There are, however, articles about topics that could be seen as agency. Together with their respective co-workers Kihlgren (79) and Ekman (80) analyzed video-tapes of morning care sessions with persons with advanced dementia and carers. The carers were taught about the Erikson (81) theory of eight stages of man and encouraged to, in a concrete way, promote the persons’ experiences of trust, autonomy, initiative, industry, identity, intimacy, generativity, and integrity during morning care sessions. The comparison of behaviors and speech before and after the intervention showed that the persons with dementia displayed more and more ability (79) and that carers who spoke the persons’ mother tongue ( Finish) were most successful in helping them use their latent abilities than carers who only spoke Swedish (80).

Persons with advanced dementia may get help to recognize and remember important themes or episodes from their life history. As the ability to recognize is better preserved than the ability to recall, they might remember a phenomenon when reminded although they cannot recall it (17). They can have an unconscious or implicit memory of past experiences (38) and often remember emotions better than facts (81). As persons with dementia best remember their life before the debut of dementia and later their earliest memory, they most easily can express their experiences by referring to memories from their childhood (54). They may for example call their mother when they feel unsecure (82). When they perceive the emotions in a conversation, they can go back in memory to an experience with the same emotions to understand what the conversation is about (83).
Thus, when a person with advanced dementia asks a carer: You are my mother, aren't you, this does not have to mean that she thinks the carer really is her mother. Instead it might mean that the interaction with the carer made the person feel being loved and when she sought an experience with the same emotional tone from the past, she found memories of her mother.

At the last stages of life, persons with advanced dementia often experience eating difficulties, especially swallowing problems (84–85). By participant observations of meals Eggers (86) described fragmentation when the persons with advanced dementia did not seem to recognize what was going on, the persons involved, the things used, or recognize themselves in the meal situation. Carers counteracted fragmentation by showing attentive interest in the interaction, valuing the persons as human beings, considering the symptoms of the dementia, and striving for mutual interpretation of the meal situation.

**Strengthening Self 3 communion**

Strengthening persons’ Self 3 seem to mainly concern themes of communion. Self 3 has been found especially vulnerable when persons with dementia are negatively positioned and do not get support of others (17, 28). This means that actions that promote the wellbeing of these persons are strengthening their Self 3. Few articles about well-being concern persons with advanced dementia due to the fact that they cannot take part in studies that require answering complicated questions. They can, however, take part in easy conversations and become observed, thus in qualitative research (87). Kaufmann and Engel (51) included persons with advanced dementia in a study based on a Tom Kitwood’s model of needs and described well-being according to the themes comfort (small pleasures of life providing relaxation, consolation); attachment (company with human beings, animals and objects, support); inclusion (being part of a community, feeling recognized); occupation (e.g., listening to the radio, exercise, participation in activities); identity (role maintenance, recognition, familiar rhythms and habits). Jetten et al. (12) reported that life satisfaction that was lower among persons with mild dementia than among persons with advanced dementia. Reasonably this could be related to anosognosia among person with advanced dementia (54). There are several means to improve the sense of well-being among persons with advanced dementia such as using multisensory stimulation for example including music and massage (88), singing (89), dancing (90), animals (91) and dolls (92). Listening to well-known songs or music and to positive stories from their own lives can strengthen the feeling of being important. Music, touch, dance and rocking can mean comfort for persons with advanced dementia (43, 69). The stimulation of the senses can be combined with ordinary nursing actions. A review of 21 intervention studies on persons with advanced dementia, in which aromatherapy, music, simulated presence (for example, listening to a tape recording of their partner), touch and multisensory stimulation, have been used, showed no proven scientific evidence but carers’ proven experience that the methods are effective, sometimes they fit, sometimes not (93).

As a positive Self 3 means that the persons with advanced dementia feel proud of themselves, loved and acknowledged other persons’ acts toward them are of utmost importance, actions that promote the persons feeling dignified certainly would strengthen self 3. Manthorpe et al. (94) described dignity as a phenomenon involving an inherent self-respect and feelings of worthiness, and being respectfully recognized
and confirmed by others. Nordenfelt (95) wrote about four variants of dignity: Menschenwurde (human dignity), which is overall other variants of dignity, that is as it is part of being human it is the same for all people; dignity as merit (e.g., being a leader), dignity as moral stature (e.g., being an altruistic person) and dignity of identity (concerns self-image, self-respect, worth and value ascribed by oneself or others). Persons’ dignity of identity can change over time, for example depending on if the persons are afflicted by dementia and how they are treated of others, which can result in physical, psychological, or emotional change or harm. Dignity of identity is connected to sense of self, and it is threatened if the persons have forgotten who they are.

The dignity as moral stature is about our moral actions. We can show that we know about their previous good properties and actions as persons with advanced dementia cannot upgrade their identity (54). Persons with advanced dementia should be cared so they can keep their experiences of human dignity, dignity as merit, dignity as moral stature and dignity of identity. When persons with advanced dementia are seen as having lost their self (4), their human dignity is questioned and there is a risk that they become treated as objects.

SPIRITUAL AND CONSOLING CARE AT THE END OF LIFE

There is so far, no cure for AD. Within approximately 4 to 8 years, dementia usually leads to dying and death, although some persons live up to 20 years after being diagnosed (96). Persons may die with dementia due to various causes (97) or due to dementia as it is a lethal disease (98).

There are few reports about needs during end of life among persons with advanced dementia. A review of 10 articles published 1993–2013 mentioned physical, social, psychological, spiritual, supportive, environmental needs and needs related to individuality. The authors emphasized that as persons with advanced dementia have severe communication difficulties, we need more research about views of stakeholders (99). Analyses of focus-group discussions at four nursing homes showed that dying was silent and silenced, emotions were put into the background and death was talked about after a person’s death. The staff did not talk about death neither with each other nor with the residents (100). This seems unfortunate as several residents have revealed that they were aware of the fact that they soon would die. One person emphasized that she was waiting to go to her real heavenly home. Another resident said that she was only living at the ward temporarily until she would meet her deceased spouse again and another one said that she wanted to listen to gospels while dying. Some did not speak about death and dying but reasoned about their funeral (60). At the last stages of life persons with advanced dementia often experience eating difficulties, especially swallowing problems (84–85). Several qualitative studies have reported that persons with advanced dementia at the end of life often exhibit aversive refuse-like eating behavior (101). There have been discussions about whether tube-feeding or comfort feeding should be used (102–103). The American Geriatrics Society (96) has recommended comfort feeding.

Spirituality has been regarded as “an integral, even fundamental, element of what it is to be a human being” (93, p. 765) and if we regard persons with advanced dementia as human beings it follows that they have spiritual needs. Spirituality among persons with advanced dementia has not, however, been
extensively studied. A literature review of scientific articles about spirituality did not report any study about persons with dementia (104) and another review study found expressed spiritual needs in 2 out of 10 articles (99). According to Kverno (93) there is a diversity of definitions of spirituality such as being connected to meaning-making. Spirituality should be understood as involving the dimensions of time and/or social space and stresses its longitudinal, habitual dimension, that is, “the values, meaning and practices most deeply ingrained at the heart of ‘who we are’ are those which have been repeated and reinforced over and over again from our infancy” (p.773) and held together with other persons. Perkins et al. (105) reported that even persons with advanced dementia were able to engage in spiritual practices that provide life meaning in accordance with their values. Observations in a nursing home showed that some persons expressed a need for religious expression or participating in religious rituals (106).

Thinking about or even experiencing that one interacts with deceased dear loved ones can provide satisfaction (60). This finding seems to represent a tendency to gerotranscendence (107) and can be understood as related to the fact that among persons with advanced dementia memory for past events is better preserved than memory of recent events (12). Swinton (108) argued that spiritual practices can be beneficial for Christian persons with advanced dementia. When their memory fails their bodily memory can be reclaimed. He referred to Bergson’s writing about a memory synonymous with recollection that represents particular things that have happened in the past and inscribes the past in the present (54). Swinton emphasized that we are embedded in our memories even when we cannot recall them, we are our memories. Persons with other religions or life views of course also need spiritual care adopted to their needs. Nursing home residents with moderate dementia expressed that religion is consolation for them (109). Persons with advanced dementia need consoling care (69, 110). The most important ingredient in consolation for these persons certainly is communion (69, 111) and it may provide them a feeling of being at home (112). However, it is most probable that they can get some moments of homecoming (60).

CONCLUSION

Persons with dementia lose parts of their self which can be noticed when considering symptoms such as amnesia, agnosia, aphasia, and apraxia. Their own sense of self can be preserved during the entire course of dementia partly due to the fact that their amnesia makes it difficult for them to upgrade their life story. Of utmost importance is that other persons understand that persons with advanced dementia still are persons and support them to feel valuable.

Conflict of interest: The authors declare no potential conflicts of interest with respect to research, authorship, and/or publication of this chapter.

Copyright and Permission Statement: To the best of my knowledge, the materials included in this chapter do not violate copyright laws. All original sources have been appropriately acknowledged and/or referenced. Where relevant, appropriate permissions have been obtained from the original copyright holder(s).
REFERENCES

1. Caddell LS, Clare L. The impact of dementia on self and identity: A systematic review. Clin Psychol Rev. 2010 Feb;30(1):113–26. http://dx.doi.org/10.1016/j.cpr.2009.10.003
2. Sabat SR. Epistemological issues in the study of insight in people with Alzheimer’s disease. Dementia. 2002 Nov; 1(3):279–93. http://dx.doi.org/10.1177/147130120200100302
3. Jenkins D, Price B. Dementia and personhood: A focus for care? J Adv Nurs 1996 Jul; 24(1): 84–90. http://dx.doi.org/10.1046/j.1365-2648.1996.16511.x
4. Millet S. Self and embodiment: A bio-phenomenological approach to dementia. Dementia. 2011Nov;10(4):509–22. http://dx.doi.org/10.1177/1471301211409374
5. Sachdev PS, Blacker D, Blazer DG, Ganguli M, Jeste DV, Paulsen JS et al. Classifying neurocognitive disorders: The DSM-5 approach. Nature Rev Neurol. 2014 Nov;10(11):634–42. http://dx.doi.org/10.1038/nrneurol.2014.181
6. Sabat SR. Dementia beyond pathology: What people diagnosed can teach us about our shared humanity. J Bioethical Inq. 2019 Jun;16(2):163–72. http://dx.doi.org/10.1007/s11673-019-09899-0
7. Sabat SR. Capacity for decision-making in Alzheimer’s disease: Selfhood, positioning and semiotic people. Aust NZ Psychiat. 2005 Nov;39(11–12):1030–5. http://dx.doi.org/10.11177/j.1440-1614.2005.01722.x
8. Sabat SR. Subjectivity, the brain, life narratives and the ethical treatment of persons with Alzheimer’s disease. Am J Bioeth. 2009 Sep;9(9):23–5. http://dx.doi.org/10.1080/15265160903098655
9. Scholl JM, Sabat SR. Stereotypes, stereotype threat and aging: Implications for the understanding and treatment of people with Alzheimer’s disease. Aging Soc. 2008 Jan;28(1):103–30. http://dx.doi.org/10.1080/01446866X07006241
10. Folstein MF, Folstein SE, McHugh PR. Mini-mental state: A practical guide for grading the cognitive state of patients for the clinician. J Psychiatr Res. 1975 Nov;12(3):189–98. http://dx.doi.org/10.1016/0022-3956(75)90026-6
11. Kramer JH, Duffy JM. Aphasia, apraxia, and agnosia in the diagnosis of dementia. Dementia. 1996 Jan;7(1):23–6. http://dx.doi.org/10.1159/000106848
12. Jetten J, Haslam C, Pugliese C, Tonks J, Haslam SA. Declining autobiographical memory and the loss of identity: Effects on well-being. J Clin Exp Neuropsychol. 2010 Apr;32(4):408–16. http://dx.doi.org/10.1080/13803390903140603
13. Hedman R, Hansebo G, Ternestedt B-M, Hellström I, Norberg A. How people with Alzheimer’s disease express their sense of self: Analysis using Rom Harré’s theory of selfhood. Dementia. 2013 Nov;12(6):713–33. http://dx.doi.org/10.1177/1471301212444053
14. Skaalvik MW, Fjelltn AM, Normann HK, Norberg A. Expressions of sense of self among individuals with Alzheimer’s disease. Res Theory Nurs Pract. 2016;30(2):161–75. http://dx.doi.org/10.1891/1541-6577.30.2.161
15. Kristensen PJL, Normann HK, Norberg A, Fjelltn A-M, Skaalvik MW. How do people in the early stage of Alzheimer’s disease see their future? Dementia. 2017 Feb;16(2):145–57. http://dx.doi.org/10.1177/1471301217658822
16. Helmes E, Østbye T. Beyond memory impairment: Cognitive changes in Alzheimer’s disease. Arch Clin Neuropsychol. 2002 Feb;17(2):179–93. http://dx.doi.org/10.1093/arclin/17.2.179
17. Sabat SR. The experience of Alzheimer’s disease. Life through a tangled veil. Oxford: Blackwell Publishers Ltd; 2001. p. 34–90.
18. Sabat SR, Cagigas XE. Extralinguistic communication compensates for the loss of verbal fluency: A case study of Alzheimer’s disease. Lang Commun. 1997 Oct;17(4):341–51. http://dx.doi.org/10.1016/S0271-5309(97)00019-0
19. Higgs P, Gillicard C. Interrogating personhood and dementia. Aging Ment Health. 2016 Aug; 20(8):773–80. http://dx.doi.org/10.1080/13607863.2015.1118012
20. Zeiler K. A philosophical defense of the idea that we can hold each other in personhood: Intercorporeal personhood in dementia care. Med Health Care Philos. 2014 Feb;17(1):131–41. http://dx.doi.org/10.1007/s11019-013-9515-z
21. Sabat SR, Harré R. The construction and deconstruction of self in Alzheimer's disease. Aging Soc. 1992;12(4):443–61. http://dx.doi.org/10.1017/S0144686X0005262

22. Harré R. The singular self: An introduction of the psychology of personhood. London: Sage; 1998.

23. Harré R, Moghaddam FM, Cairnie TP, Rothbart D, Sabat SR. Recent advances in positioning theory. Theory Psychol. 2009 Feb;19(1):5–31. http://dx.doi.org/10.1177/095935408101417

24. Sabat SR. Surviving manifestations of selfhood in Alzheimer's disease: A case study. Dementia. 2002 Feb;1(1):25–36. http://dx.doi.org/10.1177/147130120200100101

25. Sabat SR, Fath H, Moghaddam FM, Harré R. The maintenance of self esteem: Lessons from the culture of Alzheimer's sufferers. Cult Psychol. 1999 Mar;5(1):5–31. http://dx.doi.org/10.1177/1354067X9951001

26. de Boer ME, Hertogh CM, Droes RM, Riphegen II, Jonker C, Eefsting JA. Suffering from dementia – The patient's perspective: A review of the literature. Int Psychogeriatr. 2007 Dec;19(6):1021–39. http://dx.doi.org/10.1017/S1041610207005765

27. Sabat SR, Napolitano L, Fath H. Barriers to the construction of a valued social identity: A case study of Alzheimer's disease. Am J Alzheimers Dis. 2004 May–Jun;19(3):177–85. http://dx.doi.org/10.1177/153331750401900311

28. Sabat SR. Mind, meaning and personhood in dementia: The effects of positioning. In: Hughes JC, Louw S, Sabat SR, editors. Dementia: Mind, meaning and the person. Oxford: Oxford University Press; 2006. p. 287–302.

29. Kitwood T, Bredin K. Towards a theory of dementia care: Personhood and well-being. Ageing Soc. 1992 Jul;12(3):269–87. http://dx.doi.org/10.1017/S0144686X000502X

30. Hampson C, Morris K. Dementia: Sustaining self in the face of cognitive decline. Geriatrics. 2016 Oct;1(4):1–6. http://dx.doi.org/10.3390/geriatrics1040025

31. Sabat SR, Harré R. The Alzheimer's disease sufferer as a semiotic subject. Philos Psychiatr Psychol. 1994 Sep;1(3):145–60.

32. Batra S, Sullivan J, Williams BR, Geldmacher DS. Qualitative assessment of self-identity in people with advanced dementia. Dementia. 2016 Sep;15(5):1260–78. http://dx.doi.org/10.1177/1471301215601619

33. Viaña JNM, Gilbert F. Deep brain stimulation for people with Alzheimer’s disease: Anticipating potential effects on the tripartite self. Dementia. 2019 Oct–Nov;18(7–8):2836–2855. http://dx.doi.org/10.1177/1471301218761147

34. Tappen RM, Williams C, Fishman S, Touhy T. Persistence of self in advanced Alzheimer's disease. Image J Nurs Scholarship. 1999 Feb;31(2):121–5. http://dx.doi.org/10.1111/j.1547-5069.1999.tb00445.x

35. Cohen-Mansfield J, Golander H, Arnhem G. Self-identity in older persons suffering from dementia: Preliminary results. Soc Sci Med. 2000 Aug;51(3):381–94. http://dx.doi.org/10.1016/S0277-9536(99)00471-2

36. Clare L, Rowlands J, Bruce E, Surr C, Downs M. “I don’t do like I used to do”: A grounded theory approach to conceptualising awareness in people with moderate to severe dementia living in long-term care. Soc Sci Med. 2008 Jun;66(11):2366–77. http://dx.doi.org/10.1016/j.soscimed.2008.01.045

37. Eustache ML, Laisney M, Juskenaite A, Letortu O, Platel H, Eustache F, Desgranges B. Sense of identity in advanced Alzheimer's dementia: A cognitive dissociation between sameness and selfhood? Conscious Cogn. 2013 Dec;22(4):1456–67. http://dx.doi.org/10.1016/j.concog.2013.09.009

38. Kontos P. Ethnographic reflections on selfhood, embodiment and Alzheimer’s disease. Aging Soc. 2004 Nov;24(6):829–49. http://dx.doi.org/10.1017/S0144686X0402375

39. Sabat SR, Collins M. Intact social, cognitive ability, and selfhood: A case study of Alzheimer's disease. Am J Alzheimer's Dis Other Demen. 1999 Jan;14(1):11–19. http://dx.doi.org/10.1177/153331759901400108

40. Benedetti F, Arduino C, Vighetti S, Asteggiano G, Tarenzi L, Rainero I. Pain reactivity in Alzheimer patients with different degrees of cognitive impairment and brain electrical activity deterioration. Pain. 2004 Sep;111(1–2):22–9. http://dx.doi.org/10.1016/j.alzres.2003.12.007

41. Clare L. Awareness in people with severe dementia: Review and integration. Aging Ment Health. 2010 Jan;14(1):20–32. http://dx.doi.org/10.1080/13607860903421029

42. Norberg A, Melin E, Asplund K. Reactions to music, touch and object presentation in the final stage of dementia: An exploratory study. Int J Nurs Stud. 1986 Jul;40(5):473–9. http://dx.doi.org/10.1016/S0020-7489(86)00062-2
43. Asplund K, Norberg A, Adolfsson R, Waxman H. Facial expressions in severely demented patients. – A stimulus-response study of four patients with dementia of the Alzheimer type. Int J Ger Psychiatr. 1991 Aug; 6(8):599–6. http://dx.doi.org/10.1002/gps.930060809

44. Magai C, Cohen C, Gomberg D, Malatesta C, Culver C. Emotional expression during mid- to late-stage dementia. Int Psychogeriatr. 1996 Fall; 8(3):383–95. http://dx.doi.org/10.1017/S104161029600275X

45. Normann HK, Asplund K, Karlsson S, Sandman PO, Norberg A. People with severe dementia who exhibit episodes of lucidity: A population-based study. J Clin Nurs. 2006 Nov;15(11):1413–17. http://dx.doi.org/10.1111/j.1365-2702.2005.01505.x

46. Normann HK, Norberg A, Asplund K. Confirmation and lucidity during conversations with a woman with severe dementia. J Adv Nurs. 2002 Aug;39(4):370–6. http://dx.doi.org/10.1046/j.1365-2648.2002.02298.x

47. Midtbust MH, Alnes RE, Gjengedal E, Lykkeslet E. A painful experience of limited understanding: Healthcare professionals’ experiences with palliative care of people with severe dementia in Norwegian nursing homes. BMC Palliat Care. 2018 Feb 13;17(1):25. http://dx.doi.org/10.1186/s12904-018-0282-8

48. Eriksson K. Theories of caring as health. In: Gaut DA, Boykin A, editors. Caring as healing: Renewal through hope. New York: National League for Nursing Press; 1994. p. 3–20.

49. Rozum WJ, Cooley B, Vernon E, Matyi J, Tschanz JAT. Neuropsychiatric symptoms in severe dementia: Associations with specific cognitive domains the Cache County Dementia Progression Study. Int J Ger Psychiatry. 2019 Jul;34(7):1087–94. http://dx.doi.org/10.1002/gps.5112

50. Athlin E, Norberg A. Caregivers’ attitudes to and interpretations of the behaviour of severely demented patients during feeding in a patient assignment care system. Int J Nurs Stud. 1987 Feb;24(2):145–53. http://dx.doi.org/10.1016/0020-7489(87)90056-3

51. Kaufmann EG, Engel SA. Dementia and well-being: A conceptual framework based on Tom Kitwood's model of needs. Dementia. 2016 Jul;15(4):774–88. http://dx.doi.org/10.1177/1471301214539690

52. Agnew SK, Morris RG. Anosognosia in Alzheimer's disease – The petrified self. Conscious Cogn. 2009 Dec;18(4):989–1003. http://dx.doi.org/10.1016/j.concog.2009.07.005

53. Dekkers W. Dwelling, house and home: Towards a home-led perspective on dementia care. Med Health Care Philos. 2011 Aug;14(3):291–300. http://dx.doi.org/10.1007/s11019-011-9307-2

54. de Jonge DM, Jones A, Phillips R, Chung M. Understanding the essence of home: Older people’s experience of home in Australia. Occup Ther Int. 2011 Mar;18(1):39–47. http://dx.doi.org/10.1007/s11019-011-9307-2

55. Zingmark K, Norberg A, Sandman P-O. The experience of being at home throughout the life span. Investigation of persons aged from 2 to 102. Int J Aging Hum Dev. 1995 Feb;41(1): 47–62. http://dx.doi.org/10.2190/N08L-4J25-31D2-JUQA

56. Zingmark K, Norberg A, Sandman P-O. Experience of at-homeness and homesickness in patients with Alzheimer’s disease. Am J Alzheimer's Care Related Disorder Res. 1993 May;8(3):10–16. http://dx.doi.org/10.1177/15333175930080302

57. Kok JS, Berg IL, Blankevoort GCG, Scherder EJA. Rest-activity rhythms in small scale homelike care and traditional care for residents with dementia. BMC Geriatr. 2017 Jul;17(1):137. http://dx.doi.org/10.1186/s12877-017-0525-1

58. Norberg A, Ternestedt BM, Lundman B. Moments of homecoming among people with advanced Dementia disease in a residential care facility. Dementia. 2017 Jun;16 (5):629–41. http://dx.doi.org/10.1186/s12877-017-0525-1

59. Cipriani G, Danti S, Vedovello M, Nuti A, Lucetti C. Understanding delusion in dementia: A review. Geriatr Gerontol Int. 2014 Jan;14(1):32–9. http://dx.doi.org/10.1111/ggi.12105

60. Temple V, Sabat S, Kroger R. Intact use of politeness in the discourse of Alzheimer’s sufferers. Lang Communic. 1999 Apr;19(2):163–80. http://dx.doi.org/10.1016/S0271-5309(98)00020-2
63. Athlin E, Norberg A. Interaction between the severely demented patient and his caregiver during feeding. A theoretical model. Scand J Caring Sci. 1987 Sep–Dec;1(3–4):117–23. http://dx.doi.org/10.1111/j.1471-6712.1987.tb00612.x

64. Berg A, Hallberg IR, Norberg A. Nurses’ reflections about dementia care, the patients, the care and themselves in their daily caregiving. Int J Nurs Stud.1998 Oct;35(5): 271–82. http://dx.doi.org/10.1016/S0020-7489(98)00040-6

65. Astell AJ, Ellis MP. The social function of imitation in severe dementia. Infant Child Dev. 2006 May/Jun; 15(3): 311–19. http://dx.doi.org/10.1002/icd.455

66. Walmsley BD, McCormack L. The dance of communication: Retaining family membership despite severe non-speech dementia. Dementia. 2014 Sep;13(5):626–41. http://dx.doi.org/10.1177/1471301213480359

67. Hughes JC. ‘Y’ feel me?’ How do we understand the person with dementia? Dementia. 2013 May;12(3):348–58. http://dx.doi.org/10.1177/1471301213479597

68. Haggestrom, TM, Jansson, L, Norberg A. Skilled carers’ ways of understanding people with Alzheimer’s disease. Sch Inq Nurs Pract. 1998 Fall;12(3):239–66.

69. Norberg A. Consoling care for people with Alzheimer’s disease or another dementia in the advanced stage. Alzheimer’s Care Quarterly. 2001 Spring;2(2):46–52.

70. Stern DN. The international world of the infant. New York: Basic Books;1985.

71. Soderlund M, Cronqvist A, Norberg A, Ternestedt, Hansebo G. Conversations between persons with dementia disease living in nursing homes and nurses – Qualitative evaluation of an intervention with the validation method. Scand J Caring Sci. 2016 Mar;30(1):37–47. http://dx.doi.org/10.1111/scs.12219

72. Eggers T, Ekman S-L, Norberg A. Nursing staff’s understanding expressions of people with advanced dementia disease. Res Theory Nurs Pract. 2013 Feb;27(1):19–34. http://dx.doi.org/10.1891/1541-6577.27.1.19

73. Bakan D. The duality of human existence: An essay on psychology and religion. Chicago, IL: ImcNally, 1966.

74. McAdams DP. Power intimacy, and the life story: Personological inquiries into identity. New York: Guilford Press. 1988.

75. McAdams DP, Hoffman BJ, Mansfield ED, Day R. Themes of agency and communion in significant autobiographical scenes. J Personal. 1996 Jan;64(2):339–77. http://dx.doi.org/10.1111/j.1467-6494.1996.tb00514.x

76. Hedman R, Norberg A, Hellstrom I. Agency and communion in people with Alzheimer’s disease, as described by themselves and their spousal carers. Dementia (London). 2019 May;18(4):1354–72. http://dx.doi.org/10.1177/1471301217706268

77. Cissna KNL, Sieburg E. Patterns of interactional confirmation and disconfirmation. In: Wilder-Mott C, Weakland JH editors. Rigor and imagination essays from the legacy of gregory Bateson. New York: Praeger Publishers; 1981. p. 253–281.

78. Zingmark K, Sandman PO, Norberg A. Promoting a good life among people with Alzheimer’s disease. J Adv Nurs. 2002 Apr;38(1):50–8. http://dx.doi.org/10.1046/j.1365-2648.2002.02145.x

79. Kihlgren M, Kuremyr D, Norberg A, Brâne G, Engstrom B, Karlsson1, Melin E. Nurse-patient interaction after training in integrity promoting care at a long-term ward. Analysis of video-recorded morning care sessions. Int J Nurs Stud. 1993 Feb;30(1):1–13. http://dx.doi.org/10.1016/0020-7489(93)90088-C

80. Ekman SL, Robins Wahlin TB, Norberg A, Winblad B. Relationship between bilingual demented immigrants and bilingual/monolingual caregivers. Analysis of video-recorded morning care sessions in institutions by means of the Erikson theory of ‘eight stages of man’. Int J Aging Human Dev.1993 Feb; 37(1): 37–54.

81. Erikson EH, Erikson JM. The life cycle completed (Extended version). NewYork; WW Norton & Company; 1998.

82. Miesen BML. Alzheimer’s disease, the phenomenon of parent fixation and Bowlby’s attachment theory. Int J Ger Psychiatry. 1993 Feb;8(2):147–53. http://dx.doi.org/10.1002/gps.93008207

83. Piefke M, Weiss PH, Zilles K, Markowitsch HJ, Fink GR. Differential remoteness and emotional tone modulate the neural correlates of autobiographical memory. Brain. 2003 Mar;126(3): 650–68. http://dx.doi.org/10.1093/brain/awg064

84. Shinagawa S, Honda K, Kashibayashi T, Shigenobu K, Nakayama K, Ikeda M. Classifying eating-related problems among institutionalized people with dementia. Psychiatry Clin Neurosci. 2016 Apr;70(4):175–81. http://dx.doi.org/10.1111/pcn.12375
85. Kai K, Hashimoto M, Amano K, Tanaka H, Fukuhara R, Ikeda M. Relationship between eating disturbance and dementia severity in patients with Alzheimer's disease. PLoS One. 2015 Aug 12; 10(8):e0133666. http://dx.doi.org/10.1371/journal.pone.0133666. eCollection

86. Eggers T, Norberg A, Ekman, SL. Counteracting fragmentation in the care of people with moderate and severe dementia. Clin Nurs Res. 2005 Nov;14 (4): 343–69. http://dx.doi.org/10.1177/1054773805277957

87. Wolverson EL, Clarkena C, Moniz-Cook ED. Living positively with dementia: A systematic review and synthesis of the qualitative literature. Aging Ment Health. 2016 Jul;20(7):676–99. http://dx.doi.org/10.1080/13607863.2015.1052777

88. Bunn F, Lynch J, Goodman C, Sharpe R, Walshe C, Preston N, et al. Improving living and dying for people with advanced dementia living in care homes: Arealist review of Namaste Care and other multisensory interventions. BMC Geriatr. 2018 Dec; 18(1): 303. http://dx.doi.org/10.1186/s12877-018-0995-9

89. Göttell E, Brown S, Ekman SL. The influence of caregiver singing and background music on vocally expressed emotions and moods in dementia care: A qualitative analysis. Int J Nurs Stud. 2009 Apr;46(4):422-30. http://dx.doi.org/10.1016/j.ijnursst.2009.08.005

90. Palo-Bengtsson L, Ekman SL. Social dancing in the care of persons with dementia in a nursing home setting: A phenomenological study. Sch Inq Nurs Pract. 1997 Spring;11(2):101-18; discussion 119-23.

91. Kårefjärd A, Nordgren L. Effects of dog-assisted intervention on quality of life in nursing home residents with dementia. Scand J Occup Ther. 2019 Oct;26(6):433-40. http://dx.doi.org/10.1080/11038128.2018.1467486

92. Cantarella A, Borella E, Faggian S, Navuzzi A, De Beni R. Using dolls for therapeutic purposes: A study on nursing home residents with dementia. Int J Geriatr Psychiatry. 2018 Jul;33(7): 915–5. http://dx.doi.org/10.1002/GPS.4872

93. Kverno KS, Black BS, Nolan MT, Rabins PV. Research on treating neuropsychiatric symptoms of advanced dementia with non-pharmacological strategies, 1998–2008: A systematic literature review. Int Psychogeriatr. 2009 Oct;21(5):825–43. http://dx.doi.org/10.1017/S1041610209990196

94. Manthorpe J, Iliffe S, Samsi K, Cole L, Goodman C, Drennan V, et al. Dementia, dignity and quality of life: Nursing practice and its dilemmas. Int J Older People Nurs. 2010 Sep;5(3):235–44. http://dx.doi.org/10.1111/j.1748-3743.2010.00231.x

95. Nordenfelt L. The varieties of dignity. Health Care Anal 2004 Jun;12(2):69–81. http://dx.doi.org/10.1023/B:HCAN.0000041183.78435.4b

96. American Geriatrics Society feeding tubes in advanced dementia position statement. American Geriatrics Society Ethics Committee and Clinical Practice and Models of Care Committee. J Am Geriatr Soc. 2014 Aug;62(8):1590–3. http://dx.doi.org/10.1111/jgs.12924

97. Koopmans RT, van der Sterren KJ, van der Steen JT. The “natural” endpoint of dementia: Death from cachexia or dehydration following palliative care? Int J Geriatr Psychiatry. 2007 Apr; 22(4):350–5. http://dx.doi.org/10.1002/gps.1680

98. Sampson EL, Candy B, Davis S, Gola AB, Harrington J, King M, et al. Living and dying with advanced dementia: A prospective cohort study of symptoms, service use and care at the end of life. Palliat Med. 2018 Mar;32(3):668–81. http://dx.doi.org/10.1177/0269216317772644

99. Perrar KM, Schmidt H, Eisenmann Y, Cremer B, Voltz R. Needs of people with severe dementia at the end-of-life: A systematic review. J Alzheimers Dis. 2015;43(2):397–13. http://dx.doi.org/10.3233/JAD-140435

100. Osterlind J, Hansebo G, Andersson J, Ternestedt B-M, Hellstrom I. A discourse of silence: Professional carers reasoning about death and dying in nursing homes. Ageing Soc. 2011 May; 31 (4): 529–44. http://dx.doi.org/10.1017/S0144686X10000905

101. Pasman HR, Onwuteaka-Philipsen BD, Kriegsman DM, Ooms ME, Ribbe MW, van der Wal G. Discomfort in nursing home patients with severe dementia in whom artificial nutrition and hydration is forgone. AMA Arch Intern Med. 2005 Aug;165(15):1729–35. http://dx.doi.org/10.1001/archinte.165.15.1729
102. Palecek EJ, Teno JM, Casarett DJ, Hanson LC, Rhodes RL, Mitchell SL. Comfort feeding only: A proposal to bring clarity to decision-making regarding difficulty with eating for persons with advanced dementia. J Am Geriatr Soc. 2010 Mar;58(3):580–4. http://dx.doi.org/10.1111/j.1532-5415.2010.02740.x

103. Douglas JW, Lawrence JC, Turner LW. Social ecological perspectives of tube-feeding older adults with advanced dementia: A systematic literature review. J Nutr Gerontol Geriatr. 2017 Jan–Mar;36(1):1–17. http://dx.doi.org/10.1080/21551197.2016.1277174

104. Kalish N. Evidence-based spiritual care: A literature review. Curr Opin Support Palliat Care. 2012 Jun;6(2):242–6. http://dx.doi.org/10.1097/SPC.0b013e328353811c

105. Perkins C, Egan R, Llewellyn RL, Peterken B. Still living, loving, and laughing: Spiritual life in the dementia unit. J Relig Spiritual Aging. 2015 Jul; 27(4): 270–87. http://dx.doi.org/10.1080/15528030.2015.1037532

106. Schmidt H, Eisenmann Y, Golla HI, Voltz R, Perrar KM. Needs of people with advanced dementia in their final phase of life: A multi-perspective qualitative study in nursing homes. Palliat Med. 2018 Mar;32(3):657–67. http://dx.doi.org/10.1177/0269216317746571

107. Tornstam L. Gerotranscendence and the functions of reminiscence. J Aging Ident. 1999 Sep;4(3):155–66. http://dx.doi.org/10.1080/15528030.2013.855966

108. Swinton J. What the body remembers: Theological reflections on dementia. J Relig Spiritual Aging. 2014 Apr;26(2–3):160–72. http://dx.doi.org/10.1080/15528030.2013.855966

109. Higgins P. “It’s a consolation”: The role of Christian religion for people with dementia who are living in care homes. J Relig Spiritual Aging. 2014 Oct;6(4):320–39. http://dx.doi.org/10.1080/15528030.2014.880773

110. Tornøe KA, Danbolt LJ, Kvigne K, Sørlie V. The power of consoling presence – Hospice nurses’ lived experience with spiritual and existential care for the dying. BMC Nurs. 2014 Sep 3;13:25. http://dx.doi.org/10.1186/1472-6955-13-25. eCollection 2014.

111. Norberg A, Bergsten M, Lundman B. A model of consolation. Nurs Ethics. 2001 Nov;8(6):544–53. http://dx.doi.org/10.1191/096973301682553832

112. Rasmussen BH, Jansson L, Norberg A. Striving for becoming at-home in the midst of dying. Am J Hosp Palliat Care. 2000 Jan–Feb;17(1):31–43. http://dx.doi.org/10.1177/10499091001700109