Title: Do You Remember Who You Are? The Pillars of Identity in Dementia

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Abstract:

Loss of personal identity in dementia can raise a number of ethical considerations, including the applicability of advance directives and the validity of patient preferences that seem incongruous with a previous history of values. In this chapter, we first endorse the self-concept view as the most appropriate approach to personal continuity in healthcare. We briefly describe two different types of dementia, Alzheimer’s dementia (AD) and behavioral-variant frontotemporal dementia (bv-FTD). We identify elements considered important for the continuation of a self-concept, including continuation of memories, consistency in personality traits and personal preferences, and continued endorsement of certain moral tenets. We show that, depending on which element is considered most important for personal identity, continuity of a self-concept for individuals with distinct types of dementia will be affected and assessed differently. Utilizing a variety of empirical evidence, we argue that persistence of memory, personality traits, and preferences are not the most important for the maintenance of personal identity (Heiphetz, Strohminger, & Young, 2017; N. Strohminger & Nichols, 2014). Instead, as studies aimed to capture the folk-psychological view of personal continuity demonstrate, judgements about continuity depend primarily on the persistent commitment to widely shared moral beliefs (Nina Strohminger & Nichols, 2015). Because of that, we argue that individuals with bv-FTD are then more likely to lose their sense of self than individuals whose dementia primarily affects memory, such as Alzheimer’s disease. We end the chapter by showing how the importance of moral beliefs for personal identity can be used to provide guidance to healthcare professionals when considering changes in preference by individuals with dementia.

Do You Remember Who You Are? The Pillars of Identity in Dementia[[1]](#footnote-2)

1. Introduction

Psychological changes caused by dementia can raise a number of ethical questions, including the applicability of advance directives and the validity of patient preferences that seem incongruous with a previous history of values. To settle some of those quandaries, it is important to identify a conception of personal identity relevant to healthcare and clinical decision-making. There are distinct ways of characterizing personal identity. Traditionally, in the philosophical literature, the focus has been on establishing a diachronic numerical criterion of personal identity to establish necessary and sufficient conditions for maintenance of personal identity over time despite either physical or psychological changes. More recently, the focus in the bioethics literature has been on narrative identity, the view that each person’s narrative establishes their personal identity over time. A narrative establishes personal identity by offering a coherent, linear story that incorporates a person’s past and present actions and choices. Furthermore, the narrative helps maintain identity by motivating decisions and actions in the future that are congruent with the story.

In this chapter, we first propose the self-concept view of personal continuity over time.[[2]](#footnote-3) In section 2 of the chapter, we describe the self-concept view and show that we accept some aspects of the narrative identity approach but reject the requirement that personal continuity over time requires maintenance of identity. We argue that the self-concept view most closely resembles the folk-psychological characterizations of personal identity and are the most pertinent to dementia-related loss of self. In section 3, we briefly describe two different types of dementia, Alzheimer’s dementia (AD) and behavioral-variant frontotemporal dementia (bv-FTD). In section 4 of the chapter, we tackle the relative importance of the maintenance of particular psychological features for the preservation of a self-concept after the onset of dementia; these features include the maintenance of memories, consistency in personality traits and personal preferences across time, and persistent endorsement of certain moral tenets. We argue that because distinct types of dementia cause different psychological changes, concepts of self might be affected differently depending on which psychological element is identified as primary for personal identity over time. Utilizing a variety of empirical evidence, we argue that persistence of memory, personality traits, or preferences are not the most important for the maintenance of a self-concept (Heiphetz, Strohminger, & Young, 2017; N. Strohminger & Nichols, 2014). Instead, both judgments about personal continuity, made either by an individual for themselves or by an individual for others, depend primarily on the continued commitment to widely shared moral beliefs (Nina Strohminger & Nichols, 2015). Individuals with bv-FTD are, on this view, then more likely to lose their concept of self because their impairments lead to changes in moral beliefs and behavior than are individuals whose dementia primarily affects memory, such as with Alzheimer’s disease. We end the chapter by showing how the importance of moral beliefs for personal identity can be used to provide guidance to healthcare professionals when considering changes in preference by individuals with dementia.

2. Narrative Identity and the Concept of Self

There are two categories of numerical criteria for identity over time. Both aim to establish when an individual remains one and the same over time despite, sometimes, even significant physical or psychological changes. To do that, these criteria identify particular features of the individual that endure over time and that can be used to establish necessary and sufficient conditions for maintenance of identity over time. These two kinds of criteria identify either biological or psychological features as primary for maintenance of identity. Biological criteria establish identity between the various stages of a person by identifying physical features that persist over time. For example, DeGrazia (2005) argues that biological identity over time is the persistence of the same biological animal. Biological criteria, however, because of their focus on the maintenance of physical or biological features, do not capture the importance of the continuation of psychological features. In effect, because biological criteria are used to prioritize biological features of the individual, they are thought to qualify as identity, but not personal identity, criteria. Psychological criteria for personal identity are aimed at prioritizing personhood. They identify persons with a certain set of psychological features and equate personal identity over time with the continuation of those features across distinct stages of the individual’s life.

All these are third-person criteria of identity over time: First, because they do not rely on individual perspectives to establish personal identity, i.e., they do not take into account whether the characteristics selected as necessary and sufficient for the continuation of identity are actually important for maintenance of identity to individual people. For example, there are criteria of personal identity over time that require having a certain set of core memories (Perry 1978) for the maintenance of personal identity over time. But the selection of memory as the feature required for maintenance of identity is not based on the perceived importance of memory to individual people for the continuation of their identity. Second, third-person criteria aim to identify objective features that could be used to determine whether an individual is one and the same over time without relying on the particular individual’s subjective sense of continuity. In principle, a third-person criterion could be used to establish that an individual is one and the same even in situations where the individual in question is experiencing a feeling of discontinuity in personal identity. For example, an individual can continue to be the same biological animal while undergoing significant psychological change, e.g., a painfully shy person becoming an extrovert. Similarly, an individual could experience a feeling of continuity despite significant psychological changes that might challenge some accounts of psychological identity through time; for example, an individual may change a party affiliation or stop being religious and still feel like these changes have not disrupted their identity.

The focus on the third-person when establishing personal identity criteria has been criticized. For example, Schechtman (1996) argues that third-person criteria fail to capture crucial practical aspects of personal identity because they ignore the first-person perspective. To accommodate for this failing, Schechtman (1996) develops what she calls the self-constitution view, where personal identity over time is based on the ability of an individual to maintain a coherent and linear narrative. Unlike numerical criteria for personal identity, Schechtman’s self-constitution view aims to establish a relationship between the person and a particular trait, action, thought, or experience. Based on this type of account, the question becomes that of characterization, i.e., the degree to which a trait or an action could be said to characterize a particular person. A personal narrative should capture those traits and actions that characterize the person and capture the individual’s core self. According to Schechtman, the self-characterization view captures our usual notion of identity, one that is important when we wish to attribute praise or blame or explain why maintenance of identity is important. In addition, the self-characterization view concerns the sense of identity at issue when an individual is said to be undergoing an identity crisis (Schechtman 1996, p. 74). Schechtman’s view is that as long as one’s narrative maintains linearity, coherence and accuracy, the person’s numerical identity over time is maintained. This view has been adopted by DeGrazia (2005) and applied by him to a number of debates in bioethics.

Given that our aim in this chapter is to address practical applications of personal identity as they might arise for patients and caregivers, we endorse a first-person account of personal continuity. We call this the self-concept view. We opt to endorse the self-concept view, not narrative identity, to avoid the charge that identity requires specific linguistic abilities, which might exclude individuals who have limited verbal abilities, and because we reject the view that identity over time is required for the maintenance of a self-concept. Based on our view, a self-concept depends on each individual’s selection of core values, beliefs, personal interests, and characteristics. A list of traits or characteristics true of an individual is not in itself a self-concept; rather, a person develops a concept of self by incorporating only some traits she finds most important, or as Schechtman says, traits that are most self-constitutive. Because one’s self-concept is not a mere list of traits, but a selection of only some physical or psychological attributes, an individual can change over time and even appear to others as having changed a great deal without losing their sense of continuity as long as there is maintenance of certain core traits over time. This view accommodates some of the evidence presented in section 4 of this chapter, where individuals with certain kinds of dementia are able to maintain a certain sense of continuity despite significant psychological changes.

There are individual differences in concepts of self. The traits a person finds most significant for her concept of self might not overlap with what are sometimes considered core aspects of every individual. For example, characteristics that are often consider important for identity include, national origin, religion, or belonging to a particular profession. But some individuals might form a self-concept without relying on any of those traits. When generating a concept of self, one only needs to formulate a personal autobiography. The importance ascribed to features of the self is entirely individual. A person might choose her favorite characteristics and establish a hierarchy between them in any way she pleases. Such personal concepts do not establish a more generally applicable criterion for personal identity, and one person’s self-concept should not be used to adjudicate the adequacy of other people’s self-concepts. In other words, self-concepts are not normative. In principle, we do not set adequacy criteria for concepts of self although we countenance that there might be characteristics that would be required in order for an individual to be said to have an adequate self-concept. In section 4 of this chapter, we show that there are certain types of psychological traits that are more important for the maintenance of a self-concept. For example, the evidence we describe demonstrates that continued endorsement of widely shared moral beliefs, such as the belief that murder is wrong, is important for the maintenance of conceptions of self.

Unlike Schechtman’s attempt to use narrative identity also as a way of establishing that a person remains one and the same over time, we abandon the project of establishing a numerical criterion of identity, but we also endorse a distinct third-person criterion for continuity over time. Our position on numerical identity is in line with the view endorsed by Gligorov and Vitrano (2011). We maintain that continuity of self requires similarity over time, but not identity. We argue that the relationship between different stages of an individual’s life, for example, the individual at age 25, 55, and 95 is one of similarity. The person at each of those distinct moments might not maintain diachronic identity; instead, we argue that as long as the person remains sufficiently similar across time, continuity is maintained. In other words, our view is that continuity requires similarity across time, not identity. Because similarity, unlike identity, is not a transitive relationship, it can be maintained even when the individual is at distinct stages, e.g., the individual at age 25 and at age 95, might be significantly different. Our view of similarity over time is modeled on Parfit’s (1984) relationship R, which is a measure of psychological connectedness across different stages of an individual’s life. Psychological connectedness is achieved when the different stages of a person’s life are connected by chains holding between past experiences and memories of the experiences, and between her intentions and the acts in which those intentions are carried out. Psychological connections are also present when a person continues to hold beliefs, desires, and ideals, and she maintains a particular character or approach to life. As long as similarity is maintained by the interim stages, say the individual at 55 is sufficiently similar to the individual at 65, and so on, then the relationship of similarity is preserved over time. We take this view to satisfy the demands of both first-and third-person criteria. Form the first-person perspective, it is likely that an individual sense of continuity closely trails the psychological connectedness among the different iterations of their self-concept. Although an individual’s self-concept might change over time, their ability to maintain a unified self-concept will likely trail the psychological connectedness between the distinct versions of the concept. From the third-person perspective, one can use the criterion of similarity to adjudicate whether an individual remain sufficiently similar over time. For example, the similarity criterion could be used in situations where a physician needs to determine whether the self that wrote an advance directive or expressed a wish for a certain kind of medical care is sufficiently similar to the individual to whom the directive is being applied. This use of the similarity criterion will be discussed further in section 5 of the chapter.

3. Types of Dementia

According to the American Psychiatric Association’s Diagnostic and Statistical Manual (DSM-5), dementia is a major decline in at least one of the following cognitive domains: (i) complex attention; (ii) executive functioning; (iii) learning and memory; (iv) language; (v) visual spatial function; (vi) or social cognition (Association, 2013). What distinguishes major decline from minor decline is that it interferes with independence in everyday activities. In general, dementia has an insidious onset and gradual, progressive worsening –sometimes dementia can be reversed by treating its cause, but in most cases, it is irreversible. Because dementia involves interference with independence due to new cognitive limitations, it almost always implies some reduced capacity to make complex decisions, including medical decisions.

There are various ways of distinguishing types of dementia. For our purposes, we can distinguish amnestic dementias, in which loss of memory (domain (iii)) is the most conspicuous deficit; from social dementias, in which deficits in social cognition (domain (vi)) are most conspicuous, and in which episodic memory, semantic memory, and visuospatial skills are relatively spared. Alzheimer’s disease (AD) is the prototypical and most common amnestic dementia, a category that also includes Korsakoff syndrome and some post-surgical dementias, like that of the famous patient H.M., who developed complete anterograde amnesia after surgery for intractable epilepsy. Behavioral-variant frontotemporal dementia (bv-FTD) is the prototypical and most common social dementia, a category that also includes Kluver-Bucy syndrome and post-traumatic dementias like that of Phineas Gage, who manifested severe personality changes and social improprieties after highly localized brain trauma. Because the prototypes (AD and bv-FTD) are the most well-described compared to other types, we will focus on these specifically.

The earliest and most conspicuous deficit in Alzheimer’s disease is impairment of episodic memory, though visuospatial skills and semantic memory are also affected to a lesser degree. Initially, there is difficulty encoding new memories, while there is preservation of immediate recall (e.g., rehearsing a phone number), procedural memory (e.g., knowing how to do long division), and recollection of remote facts (e.g., childhood events). As the disease progresses, the episodic memory deficits worsen to the point that patients struggle to recall core personal events and relationships. Personality changes occur throughout the disease course and are characterized by apathy, neuroticism, and decreased conscientiousness and insight.

In contrast to Alzheimer’s, the earliest and most conspicuous dysfunction in bv-FTD is impairment in social interactions due to personality changes, with relative preservation of memory. The criteria for bv-FTD require that three out of the following six symptoms be persistent or recurrent: (i) behavioral disinhibition (socially inappropriate behaviors, loss of manners or decorum, impulsiveness or carelessness); (ii) apathy or inertia; (iii) loss of sympathy or empathy (diminished response to other people’s needs or feelings, or diminished social interest or personal warmth); (iv) stereotyped, compulsive or ritualistic behavior; (v) hyperorality and dietary changes; (vi) executive deficits with sparing of memory and visuospatial skills (Rascovsky et al., 2011). Typically, patients have very little insight into the changes in their personality. Personality changes rise to attention when the patient becomes apathetic or even antipathetic about prior interests and relationships, and becomes preoccupied with new, strange interests, such as unusual dietary fads or oral fixations (e.g., chewing gum all day), compulsive behaviors (e.g., repeatedly vacuuming the house), or uncharacteristic enthusiasms (e.g., an obsession with painting); it is not uncommon for patients in the early stages of the disease to develop the “facilitation” of creativity that inspires zeal for artistic expression. Family members may not realize that these personality changes are pathological until the patient becomes excessively disorganized, aggressively hostile without provocation, or embarrassingly disinhibited.

There is some overlap in the clinical features of AD and bv-FTD, but the differences are more striking than the similarities. Both conditions involve personality changes, including apathy and lack of insight, and both involve some degree of memory impairment and executive dysfunction. However, bv-FTD is characterized by startling personality changes with relative preservation of memory; the personality changes involve core features of the self, including revised political and religious tenets, dramatically shifting dietary preferences, altered daily habits and routines, and decline in general degree of care and affection expressed toward family, friends, and acquaintances. The symptoms of AD are almost the reverse: progressive episodic memory loss with relatively minor personality changes of executive dysfunction (which revolve around neuroticism and decreased conscientiousness), rather than relationships to others and to distinctive features of personality. In general, the lack of insight into the dementia that is shown by individuals with advanced bv-FTD is more severe than in advanced Alzheimer’s, especially with respect to personality changes.

4. Elements of a Self-Concept

As was described in section 2, having a self-concept requires an individual to identify certain personality traits, preferences, moral values, and a trail of past actions. As we stated in that section, we do not establish any *a priori* requirements for an adequate self-concept. And because our view relies on first-person rankings of traits most important for the formation and maintenance of a concept of self, an empirical approach can be used to identify which psychological features are most important to people when it comes to the maintenance of self-concepts over time. Although these data should not be seen as providing a normative ideal for what is required for a good self-concept, they can be used to make predictions about which traits might be most important to individual people to maintain their self-concept.

The deficits associated with AD and social dementias like bv-FTD can serve as test cases to help identify whether any particular psychological ability is most important for the maintenance of the self-concept. Amnestic dementias like AD can help determine the importance of memories as the primary pillar of continuity, while bv-FTD is a test case for the significance of changes in preferences, values, and behavior. In what follows, we will describe a number of studies that identify the relative importance of certain psychological abilities for the maintenance of a self-concept. The methodology they use is heterodox, and many of the studies shift between speaking about identity over time and speaking about a sense of self. Nonetheless, most of the studies rely on what can be characterized as a first-person characterization of a concept of self, i.e., they ask either patients or healthy individuals to identify features most important for the maintenance of self. For example, they utilize tests that prompt individuals to describe their self-concept or they provide participants with scenarios of imagined changes to gauge to what extent they think such changes would affect their own view of personal continuity. We do not interpret these data as providing guidance as to the most adequate numerical criterion of identity as they were described in section 2.

As mentioned in section 2, some views on third-person identity over time identify memory as important for continuity. This view has initial plausibility even when one adopts a self-concept view of personal continuity, as it would stand to reason that all memory, but in particular, autobiographical and episodic memories would be a source of self-knowledge that would help ground one’s concept of self.[[3]](#footnote-4) There are, however, several studies that undermine the importance of even episodic memories, for the maintenance of self in individuals with Alzheimer’s disease. Eustache et al. (2013) assessed the concept of self in patients with advanced Alzheimer’s by using the I-AM test which requires spontaneous self-definition by finishing sentences of the form “I am…” with a self-description. They also utilized the IMAGE test, which requires rating of self-descriptive statements, such as “I’m an honest person” or “I tell lies far too often.” They compared the performance of individuals with AD to those of healthy elderly controls. The study showed that even individuals with advanced AD had a persistent sense of self: individuals were retested two weeks after the initial test, and the results of the tests remained the same, indicating that their sense of self remained steady over two weeks. The most notable difference between the two populations in the study, those with AD and normal adults of similar age, was that patient’s with AD, in mild to severe stages of the disease, on average estimated their chronological age at 14 years younger than they actually were. The maintenance of sense of self despite disease was credited to the maintenance of declarative memories,[[4]](#footnote-5) while the inability to estimate their age correctly was thought due to their deficits in episodic memory, which prevented them from updating their sense of self.

Another study by Addis and Tippett (2004) investigated the connection between concepts of self in individuals with AD and their autobiographical memory. Utilizing the Twenty Statement Test, Addis and Tippett discovered that patients with AD in the mild-to-moderate stages had what was characterized as a “weaker sense of identity”; their answers to questions were more abstract and vaguer than those of healthy elderly individuals. The components of identity as identified by the Twenty Statement Test, however, were preserved in individuals with AD. Moreover, the deficits in memory identified through the Autobiographical Memory Interview only very weakly correlated with their performance on the identity measures, showing that deficits in autobiographical memory do not seem to have a very significant impact on maintenance of a concept of self in patients with AD.

Another initially plausible view would have it that maintenance of particular personality traits is required for maintenance of self-concept over time. Changes in personality traits, for example, a shy person becoming more social, might precipitate a discontinuity in a self-concept. The importance of maintaining core personality traits has been cited as the reason against the use of pharmacological and other medical means of personality modification (Erler, 2011; Kass, 2003). A number of recent studies designed to identify the essential aspects of the folk-psychological conception of self demonstrated that persistence of particular personality traits was not considered most important for continuity. In a series of studies, Strohminger and Nichols (2014) investigated which changes to an individual’s psychology would be judged as having the greatest impact on personal identity and concluded that changes in morality had the greatest impact on judgments of personal continuity. Changes in personality traits, such as shyness or absentmindedness, were considered second most important after changes in morality. One of the scenarios asked participants to imagine meeting an old friend and then to imagine that they had changed in some way. The changes that were judged the least significant for continuation of identity included changes in desires. It is important to note that changes in desires and preferences included changes in sexual orientation, which makes it even more surprising that that category was not considered more important given that sexual orientation is often considered crucial for conceptions of self.

Strohminger and Nichols (2014) also investigated more targeted changes, such as asking participants to imagine a person taking a pill that could change a more specific aspect of themselves. This approach revealed that changes in morality, including changes in moral behavior (e.g., lying or cheating) and moral traits (e.g., being compassionate or generous), were considered the most determinative of discontinuity in personal identity. In a study further investigating the importance of moral tenets on the continuation of identity, Heiphetz et al. (2017) identified which moral tenets were judged the most important to preserve identity. They investigated the impact of both rejections of widely held moral beliefs – that murder and pedophilia are wrong, for instance – as well as the significance of switching sides on controversial moral beliefs, such as believing, against earlier convictions, that abortion is morally wrong or that euthanasia is permissible. In this study, they investigated both first- and third- person judgments of importance for continuation of identity. In other words, they asked people to imagine a change in moral beliefs for themselves and for somebody else and then asked them to judge the significance for their identity and for the identity of some other person. In both instances, participants judged that changes in widely held moral beliefs were the most significant for the maintenance of personal identity when the participants were making judgments for themselves and when they were judging for other people.

A possible explanation for why continued commitment to widely held moral beliefs is judged to be so crucial for the maintenance of personal identity is captured by the community hypothesis (Heiphetz et al. 2017), which is the view that sharing certain beliefs is particularly important for maintaining membership in a particular community. Endorsement of widely shared moral beliefs allow people to participate in and belong to a community, and losing communally shared beliefs could challenge continued membership in that community. Moreover, membership in a particular community, such as being a member of a particular religious group, might be constitutive of an individual’s concept of self (Turner & Tajfel, 1986). Thus, being excluded from the relevant community might challenge self-concepts.

There is evidence that communal membership and identity is important to individuals with dementia. Cohen-Mansfield et al. (2000) sought to determine to what extent role identities are preserved after dementia onset. The categories of roles investigated by the survey included occupational roles, e.g., a person’s role as a nurse or a teacher; family roles, e.g., one’s role as a parent or a sibling; and leisure activities, e.g., an individual’s role as a tennis fan or book club member. The questionnaire asked participants to rate their role identities and compare how important these roles were to them in the past and how important they were to them at the time of the survey. The responses indicated that role identities had changed in importance over time. For example, individuals with dementia considered occupational role identity the least important, while their family role identity remained more important. This study provides some indication that belonging to a family and maintenance of one’s role in the family remain important sources of an individual’s concept of self even after the onset of dementia.

If the community hypothesis is correct and it helps explains the prioritization of widely held moral beliefs for the persistence of a self-concept, then it would be particularly interesting to determine whether preferences not explicitly moral but required for membership in a community or religious group would be prioritized for individuals from those communities. For example, if the commitment to a particular dietary regimen is required for belonging in a particular religious group, then changes in dietary preferences might be considered as important as changes in widely held moral beliefs because they are crucial to being part of a specific community. Similarly, changes in memory, personality, and preferences might become more important if they are crucial to maintain role- or group-identity in specific communities. Most studies investigating the folk concept of identity found that changes in physical abilities, including perceptual and cognitive abilities, were judged to have little impact on continuation of identity. However, if physical skills were central to an individual’s belonging to a community, say being a ballet dancer or rock climber, perhaps loss of those abilities would be more consequential to those individuals as it might prevent them from continuing to be part of their communities. In other words, the judged importance of an individual’s psychological or physical features would depend on those features’ relevance for membership in a specific community.

Given what we already know about the relative importance of moral beliefs to self-concepts, one would expect that changes in morals or changes in moral behavior might be the most determinant of the caregiver’s assessment of identity change in individuals with dementia. Strohminger and Nichols (2015) surveyed caregivers or family members of individuals with AD, bv-FTD, and amyotrophic lateral sclerosis (ALS) to determine to what extent psychological and physical changes caused by neurological disease had affected personal identity. The study demonstrated that although the daily functioning of individuals with ALS was the most affected, caregivers of individuals with ALS were the least inclined to judge them as having changed. Individuals with AD were judged to have the least change in daily functioning (although this might depend on the severity of the disease), yet they were more likely to be perceived by their loved ones as having changed and even as having become ‘like a stranger.’ Individuals with FTD were the most likely to seen by their caregivers as having changed or as having become like a stranger. These findings support the research indicating that changes in widely held moral beliefs are thought the most significant for the maintenance of personal identity. As individuals with bv-FTD are more likely to exhibit morally, and sometimes even legally, prohibited behavior such as stealing, pedophilia or even murder (Darby, Edersheim, & Price, 2016), it is to be expected that their relatives would experience those changes as very significant for identity. It is of note that, as was described in section 3 of the chapter, individuals with bv-FTD lose insight into their disease and become unable to notice changes in their personalities and eccentricities in their behavior. Several studies note the discrepancy between the patient’s and caregiver’s judgments about continuity of self when it comes to individuals with bv-FTD (Darby et al., 2016; Rankin et al., 2005). In the following two sections, we will assess how the deficits experienced by individuals with distinct types dementia affect self-concepts.

5. Changes in Preference and Changes in Self-Concept

To highlight the importance of personality changes in dementia to clinical ethics, we will now gauge how knowing more about the relative importance of the elements of a self-concept can help with decision-making when patients with dementia begin expressing preferences that are incongruous with their previous wishes.

In addition to quandaries about advance directives, which apply strictly to medical preferences, an ethical dilemma that arises in taking care of patients with dementia is whether to respect changes in preferences when they are incongruous with the individual’s prior wishes or values. As was described in section 3, bv-FTD can often result in changes in dietary preferences and the development of new interests or compulsions. Similarly, individuals with AD could simply forget their prior commitments to certain dietary restrictions or other long-term commitments, which could result in changed preferences. An example often invoked in this context is of an individual who, after developing dementia, has started expressing preferences incompatible with their previously held religious beliefs. For example, a rabbi might wish to start eating shellfish or some other non-kosher food after developing bv-FTD. If the rabbi is in a nursing home, the question becomes whether the rabbi’s caregivers should respect his or her wishes and let the patient eat non-kosher food. Intuitively it would seem that it is wrong to allow the rabbi to eat shellfish, even if the patient consistently expresses that preference. Intuitions usually switch if the change in preference is perceived as innocuous, such as the rabbi wants to eat sweets even if earlier in his life he never enjoyed eating dessert.

There are variety of reasons why one might make a distinction between eating dessert and eating shellfish in this particular context. One could make the argument that the patient is no longer making authentic choices or more precisely choices congruous with their earlier concept of self. Or one could appeal to capacity and argue that the patient no longer has the capacity to make decisions about dietary practices. Both of these ways of responding to the problem would require that both preferences be either rejected or accepted. If one argues that the patient’s preferences are somehow inauthentic because of a large change in the patient’s self-concept, then all changed preferences should be rejected, whether it is to eat shellfish or to eat sweets. Similarly, if a patient is deemed to lack capacity to make their own decisions, then any new preferences should be rejected because they are not the result of an autonomous decision. These approaches do not offer a way of accommodating the intuition that there is a difference between preferences. The research on the importance of moral beliefs for the continuity of self-concept offers a way of differentiating between the preference that contravenes one’s religious commitments and the one that merely indicates a departure from a previously established habit.

As previously described, research by Heiphetz et al. (2017) indicates that the maintenance of identity depends greatly on the maintenance of beliefs that make it possible for an individual to continue being part of the community. Moreover, the study on role identity by Cohen-Mansfield, Golander, and Arnheim (2000) showed that family-role identity tends to remain preserved even after individuals with dementia forget or deprioritize all their other role identities. Hence, insofar as maintenance of a concept of self through role identity can improve or promote the wellbeing of individuals with dementia, decisions about respecting patient preferences and desires should in part consider how respecting those preferences might affect the patient’s role identity as well as their communal identity. Allowing a rabbi to eat non-kosher food could disrupt both his family relationships and his continued acceptance within the religious community. Eating cake would not have such an effect. Thus, one could distinguish between the new desire to eat non-kosher food and the increasing desire to eat dessert by appealing to the importance of each of those desires with respect to the maintenance of a self-concept. There are a couple of reasons why working to preserve a conception of self might be important. First, personal discontinuity due to the loss of a self-concept might diminish quality of life. Second, individuals with dementia become increasingly dependent on their family for both daily leaving and for emotional care. Maintenance of a self-concept might make it easier for the family to continue caring for the patient, which in turn promotes the patient’s quality of life.

As we described earlier, patients with bv-FTD experience significant changes, such as behavioral disinhibition that results in socially inappropriate behaviors and loss of sympathy and empathy. These changes can diminish these individuals’ abilities to act in accordance with commonly accepted moral norms. Indeed, some patients with bv-FTD engage in behavior both illegal and immoral actions, including pedophilia, public masturbation, physical assault, hit and runs, and theft (Darby et al., 2016). It is clear that behavior that is both harmful to others and legally prohibited cannot be condoned by those caring for individuals with bv-FTD. Decisions become harder when the behavior is not criminal, but might be considered by some as problematic, such as addiction to pornography. Even if this habit might not cause physical harm to others, it could disrupt family relations. If one takes seriously the view that continuity of a self-concept depends on the maintenance of certain basic moral beliefs that are required for the maintenance of community relations, then in some situations it might be advisable to curb behavior that disrupts the patient’s family relations for the sake of maintaining their self-concept. However, one must always seek a balance between limiting an individual’s choice and promoting continuity of self, because even for patients who lack decisional capacity and cannot take responsibility for their actions, restrictions of liberty can decrease quality of life.

There is a developed literature in bioethics on the relevance of personal identity on advance directives (Buchanan & Brock, 1989; Dresser, 1994, 1995; Dworkin, 1986). Within this literature, commentators focus on whether changes in identity could invalidate advance directives. For example, if a person with an advance directive were to change so significantly that they could be judged to be a different person, it might be the case that an advance directive no longer applies. Much of the debate about the validity of advance directives in this context either assumes a kind of numerical criterion of identity where sufficient personality changes result in a discontinuity of identity, such that an individual before and after dementia would be two different people. As we argued in section 2 of the chapter, we reject criteria for numerical identity and adopt the criterion of similarity. We maintain that caregivers could decide when advance directives apply based on the degree of similarity between the individual who wrote the directive and the patient who now might be subject to this directive. If an individual after dementia is still sufficiently similar to the individual who formulated the directive, then the directive might apply. If, however, the individual is sufficiently dissimilar, the advance directive might no longer be applicable. It is important to note, however, that in many situations, adjudicating degrees of similarity, as per our view, or identity would not be required in order to determine whether a directive still applies to the patient with dementia.

There are two central questions with regard to the applicability of advance directives, and each one of them can be resolved in distinct ways. The first question is whether an individual with dementia ought to be allowed to revoke or change their advance directive. The answer to this question does not require a solution to whether an individual before or after the onset of dementia symptoms is the same person. This is in part because of the restricted ways in which patients can currently formulate advance directives. Some of the most common advance directives are proxy designations where an individual identifies somebody they know to make decisions for them when they lose capacity because of illness. Another type of advance directive is a Do Not Resuscitate (DNR) order and a Do Not Intubate (DNI) order, which obligates physicians to refrain from implementing these life-sustaining measures, including for patients who no longer have decision-making capacity. Some states in the United States also have Medical Orders for Life-Sustaining Treatment (MOLST), which provide patients with the ability to give specific guidance to physicians about resuscitation, intubation, and the use of antibiotics. In order for the patient to revoke an advance directive, they must have decisional capacity. As was discussed in section 3 of the chapter, a diagnosis of dementia causes cognitive impairments that impede independence, which implies that dementia usually diminishes an individual’s capacity to make some medical decisions. As dementia progresses, patients will ultimately become unable to make all medical decisions. This means that an individual with dementia will eventually not be able to revoke an advance directive simply because she is no longer judged competent to make medical decisions for herself or for anybody else. This makes the question of identity irrelevant.

The second question pertaining to the applicability of advance directives to individuals with dementia is whether an individual taking care of a patient with dementia ought to respect the prior-instituted advance directive. Here, the questions of identity may become relevant. Buchanan & Brock (1989) provide a solution that might help in making decisions for individuals at the very end stages of dementia. They argue that in most situations where advance directives become relevant for medical decision-making, patients have usually lost most of their psychological functioning such that they are no longer persons at all. These would be situations where one would make decisions for individuals at the very end of life who have lost all of their psychological functioning. In this case, one could revert to DeGrazia’s biological criterion and argue that the advance directive still applies because the patient is still the same biologically defined creature. We think that employing a biological identity criterion is an adequate answer in most cases where individuals are at the very end stages of dementia. It is important that individuals at the very end stages of dementia lose even the most basic elements of psychological function required for maintaining consciousness or interacting with their environment. In such cases, it would not be controversial to say that an individual with dementia no longer has a concept of self and is no longer a person. Biological criteria of identity are not criteria of personal identity because they do not rely on the maintenance of psychological function to fix identity over time, and can be used to determine whether an individual is the same biological animal over time.

In earlier stages of dementia where individuals with dementia are still able to maintain a self-concept, we take the view that the criterion of psychological similarity and continuity provides the right answer, which is that in cases where the individual with dementia is sufficiently similar to the person before the onset of dementia symptoms, advance directives should apply. To determine similarity and to promote maintenance of a self-concept, caregivers could utilize evidence about the importance of moral beliefs to self-identity, using changes in moral commitments as one of the indicators of discontinuity of self-identity. We would venture a guess that situations in which individuals would still be considered persons, based on Buchanan and Brock’s criteria, but could be judged to be sufficiently dissimilar because they have stopped endorsing communally endorsed moral beliefs, would most likely arise for patients with bv-FTD. In situations such as these, advance directives might no longer apply, and decisions about whether to implement the advance directives should be made based on judgments about quality of life rather than judgements about maintenance of a self-concept.

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2. Throughout the chapter we use the term self-concept and concept of self interchangeably to designate the view formulated in the second section of the chapter. [↑](#footnote-ref-3)
3. Episodic memories are memories of everyday events that are associated with a particular time or location, such as the memory of a witnessed car accident. Autobiographical memories are a subset of episodic memories that are of episodes of an individual’s life, such as the memory of one’s first kiss. [↑](#footnote-ref-4)
4. Declarative memories are memories of facts, such as knowing the name of the capital of France. [↑](#footnote-ref-5)