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Dementia and the Fragility of Self: Navigating Ethical Considerations in Medical Decision-Making

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DEMENTIA AND THE FRAGILITY OF SELF: NAVIGATING ETHICAL CONSIDERATIONS IN MEDICAL DECISION-MAKING

By

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Abstract

As the global population ages, the incidence of degenerative memory disorders such as Alzheimer's and dementia is expected to rise. The frequency of complex medical decision-making challenges for these patients will subsequently increase. It is now common practice for patients to provide advance directive outlining the care they wish to receive; in the case they are deemed incompetent to preform adequate decision making. However, patients with dementia occasionally express wishes contrary to those stated in their advance directives. This divergence creates ambiguity about which wishes should be honored and for who those wishes are being honored for. I aim to address this question through the lens of personal identity. By examining several theories of persistence of personal identity through memory loss, I argue that the significant mental changes associated with dementia challenge the effectiveness of applying prior expressed articulation and advance directives. We should treat the current expressed wishes of patients with dementia as legitimate guides to the nature of care they receive. We need to reassess our over-reliance on advance directives and incorporate the current expressed wishes of patients with dementia into the medical decision-making process.

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Incipit Vita Nova

Section 1 – Complications in dementia care[1]

The complicated and rapidly changing ethics of dementia care, in conjunction with the exhausting process of caring for people with dementia, generate numerous issues surrounding the formation of care standards. While theorists fight to identify and solve stigma at the intersection between aging care and disability, physicians and medical professionals strive to find better medical solutions for patients with dementia. There is an important precursor to these questions of how we should treat patients with dementia. We need to first ask "Who are we treating?" Dementia often creates a patient with little or wavering psychological connection to their past self. It is often unclear whether clinicians are treating the current person with their current wishes for care or the past person with their prior expressed wishes for care.

Currently, most of the decision-making falls on prior expressed articulation in the form of verbal or written expressions of medical wishes if they are provided. At a time when the patient was capacitated, they could clearly state their choices for medical care in case they became incapacitated (Post 37). But the nature of dementia upends the superficial simplicity of this system. In the case of coma patients or patients with traumatic injuries, it is common practice that we honor their prior expressed wishes about care their wish to receive. But coma and trauma patients often do not experience the extreme and complete psychological changes characteristic of dementia (Sudarsanan 260). When they do, there is often a strong reason to disregard their wishes (Post 21). Many are likely to recover, and

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[1] Some of the language used in this thesis, including words such as *demented, disease, aged* and *senile,* are no longer considered appropriate terminology to describe people with dementia. In general, using person first language like *people with dementia* more accurately emphasizes the patient's humanity and limits the confinement of their individuality to a medical diagnosis. However, some research and philosophical writings presented in this thesis predate these term updates, so I will occasionally use them to describe dementia and other degenerative diseases to align with terms used in literature.

therefore would experience harm by medical treatment done against their wishes. Others will never recover, and therefore harm is done to the person they used to be in forcing or removing treatment against their wishes (Dworkin 227). Dementia is different. As discussed later, dementia can entail a slow decline in memory and cognitive function that can play our over periods as long as twenty years. The losses come in steps, with patients dropping off and deteriorating rapidly, but then remaining congruent until the next drop. Consider the following patient:

> The patient is a male in his early 60s who has high blood pressure, high cholesterol, diabetes mellitus, and atrial fibrillation. Nearly two years ago, the patient developed an abrupt cognitive decline. Since that time, he has been experiencing stepwise declines in his functioning. His family reported that he now has attention problems, slowed thinking, reduced reasoning, and increased falls. He also seems to be more impulsive than he used to be (Schroeder).

In cases like this where the step-like deterioration is relatively obvious, it can be unclear when the patient loses the ability to make decisions and becomes incapacitated. For example, even when a patient can accurately communicate, he could still be so impulsive and cognitively impaired that he should no longer be allowed to make decisions for himself. He cannot accurately assess his own wants or needs. I believe this is one of the fundamental differences between an advance directive for someone who was previously capacitated and becomes incapacitated and an advanced directive for someone with dementia.

In some dementia cases, there is a perceived or actual break in personhood. But what makes dementia so different from severe and repetitive concussions in a football player? Most people would not question whether a football player remains the same person after a traumatic brain injury (TBI). This could be partially due to medical differences. These players often experience changes in personality such as increased aggression and decreased cognition. However, in most cases they remain able to identify with themselves and their lives before their injuries (Sudarsanan 260). We treat a football player with a TBI as the same person, respect her wishes, and defer to her surrogate decision maker. But with dementia, this same logic is often not followed. Patients with dementia often express little connection with their former lives, families, and memories (Schroeder). Intuitively, it seems strange then to blindly enforce advance directives on a patient who may actively resist those directives. But they inhabit the same body and maintain the same family and life experiences. I will attempt to make sense of this discrepancy in intuition by exploring the innumerable complications that arise in cases where there is ambiguity between which medical decisions should be honored and whose interests are being service by honoring them.

Section 1.1 - Aging in America

Dread of aging is steeped in American cultural history (Ballenger 23). In the beginning of the twentieth century, Alzheimer's disease was first denominated to differentiate between pre-senile and senile dementia. Emil Kraepelin and Alois Alzheimer would later suggest that they believed their discoveries constituted a new category of diseases separate from senile dementia (Ballenger 41). It was not until the late 1960s that psychiatrists and neurologists such as Kraepelin and Alzheimer began to question the categorization of senility. A common practice of American physicians at the time was to disregard medical issues prevalent in elderly people as a normal part of the aging process (Ballenger 41). Dementia began to shift from a social problem to a scientific problem. Many critics believe this led to the biomedicalization of a disease with strong social implications. In other words, dementia became a medical problem that could be solved with scientific research. Research shifted away from social solutions, such as ensuring proper accommodations, toward the use of medication (Ballenger 122). As the number of people over 65 rises exponentially and the number of patients with dementia subsequently increase, a view of Alzheimer’s patients as victims of a stolen life has remained characteristic of Alzheimer’s in the United States (Stites 264).

Since the 1950s, the American medical system has become increasingly sympathetic to the patient’s ability to accept or decline care, even against accepted medical standards (Kilbride 1633). With this acceptance of autonomy as a driving factor in medical decision making, issues surrounding the definition of an individual, the relationship and persistence of self, and the role of the physician have all complicated autonomy’s dominion over medical decision making (Post 120). In dementia cases where patients suffer radical breaks from self and identity, it is important to question the all-encompassing power of autonomy in health care decisions. Advance directives still stand as viable decision-making standards in these cases, despite instances of intense patient resistance against the wishes they previously expressed in their advance directives (Post 127).

Section 1.2 - Medical research and diagnostic standards of dementia

Medical research on the treatment of dementia, which includes Alzheimer’s disease, Creutzfeldt-Jakob disease, Parkinson's disease and several other degenerative disorders, is rapidly expanding. This is partly due to rapidly aging population in countries like the United States increasing the number of patients with dementia (FDA). Though typical aging does decrease the function of the brain to some degree, Alzheimer’s is a significant and widespread loss of function in neurons, usually caused by the abnormal buildup of amyloid (protein) plaques and tau tangles (Lubinski 22).

The current diagnostic standards of dementia include medical history, cognitive and physical examination, laboratory testing, and brain imaging (Arvanitakis 1589). This helps physicians identify markers like severity and causes, as defined by the Clinical Dementia Rating and Global Deterioration Scale (Arvanitakis 1590). Generally, these severity markers are placed on a temporal scale based on progressions: mild cognitive impairment, mild dementia (early stage), moderate dementia (mid stage), and severe dementia (late/advanced stages). These stages align with the neural degenerative timeline of the brain in patients with dementia (Lubinski 24). Alzheimer's disease typically begins with the disruption of neurons in the entorhinal cortex and hippocampus, thereby affecting a patient's memory. Later, patients lose function in the cerebral cortex, which controls the capacity for language and reasoning. This decline affects a patient's social behavior and impacts other parts of the brain that control movement and bodily function (Lubinski 26). Alzheimer's disease is ultimately a fatal disease, though patients can live 20 years after their diagnosis (Arvanitakis 1590). In 2022, new breakthroughs in medical treatment have included approval of medications such as Aducanumab. These drugs target amyloids (protein plaques) and improves cognition in mild cases of dementia (FDA). They can in some cases reverse symptoms (FDA). There are currently no approved treatments for mid-stage and late-stage dementia. While the actual effectiveness of new early-stage treatments remains hazy, there are several emerging drugs with promising results (FDA).

For this paper, I use *dementia* in reference to the irreversible and incurable decline of cognition due to the damage or loss of nerve cell connectivity within the brain. This decline is usually characterized by loss of memory and reasoning capacities. Living with dementia can be hard to predict in general terms. Because of the natural complexity of human neurology, this loss of connectivity can affect patients in dramatically different ways. I will discuss this in more detail later. Testimonials from people with dementia can provide vital insight into the mental states of people with dementia. Geri Taylor was diagnosed with mild cognitive impairment in 2012:

> At first, it was small things. Ms. Taylor repeatedly complained to her husband that the blinds were broken, yet every time he went to fix them, she had been pulling on the wrong string. However, soon her symptoms became more apparent, diverging from the normal amount of forgetfulness. She was incredibly distressed to discover that, upon looking into her bathroom mirror, she no longer recognized the person looking back at her, inciting her to seek treatment from a neurologist. As her diagnosis progressed, time began to meld together, as her brain lost the ability to differentiate between events in the past, the present, and the future (Kleinfield).

Ms. Taylor's case is typical of dementia cases where, though they have lost much of their former cognition, patients still express happiness and fulfillment (Post 127, 141). Ms. Taylor has become an avid photographer after her diagnosis. However, while cases like Ms. Taylor’s are common, there are many patients with dementia who experience heightened anger and confusion as the disease progresses. This has contributed to stereotypes of dementia as a violent or fundamentally unhappy state, characterized by extreme aggression (Magai 383). Despite this stereotype, many patients with moderate dementia can express wishes about their care even though they experience severe memory loss (Post 127, 141). The value that those wishes would provide in informing treatment decisions remains controversial.

Section 1.3 - Theoretical limits of advanced directives

In modern medical treatment, autonomous and competent individuals are viewed as having the most self-knowledge and the ability to make the most accurate decisions about their own medical treatment. Therefore, advanced directives are one of the most important decision-making factors in medical care. In general, this respect for autonomy also protects individuals who make decisions without a full understanding of the consequences of those decisions, even if those decisions go against generally acceptable social norms (Childress

53). For example, a patient with skin melanoma can refuse treatment for this curable yet deadly cancer. This is against the general standards of best interest. However, their refusal is accepted as long as they are deemed capable of decision making and their choice to refuse treatment is not rooted in incompetence. Though accepting cancer treatment is the social precedent, less than 1% of patients refuse all conventional treatment (Frenkel 236). There are cases where patients deem it in their best interest to refuse treatment, and a respect for autonomy requires a respect of these decisions. Their refusal may be for moral or religious reasons, or purely because the patient does not want the treatment. If they are deemed competent, their wishes should be respected.

Though advance directives are currently the standard for decision making for people with substantial cognition loss, their use is not without controversy. In Rebecca Dresser's *Dementia, Disability, and Advance Medical Directives: Defensible Standards for Dementia Care,* she argues that these decisions to withdraw care in dementia cases come from a fundamental misunderstanding of disability by people who write advanced directives. She claims persistent knowledge deficits inhibit people without dementia. They are unable to fully conceive a life without their present amount of cognition and therefore can never make accurate predictions on the quality of care they will want (Dresser 2020 78). Ashley Taylor's *Lives Worth Living: Theorizing Moral Status and Expressions of Human Life* outlines how the socially constructed norms of cognitive ability are perpetuated by academics to form false assumptions about human ability. Taylor argues that many people have an inability to empathize with patients with dementia and often see them as subhuman, leading them to express wishes in advance directives that reflect that idea.

Dresser argues that advance directives are a way for patients to express what they determine to be "the good death" and dictate to doctors the most fitting way they believe they should die (Dresser 2020 86). Imagine two patients who, like most people, have minimal knowledge about the health care system and the different medical treatments that are available to them (Dresser 2020 78). Assume that both patients have both written advanced directives and expressed to their surrogate decision makers that they would never want to be on prolonged artificial nutrition:

> Patient A comes into the hospital after a severe car accident, is in a coma and pronounced brain dead by the attending physician. Given the advanced directive, the surrogate decides not to provide artificial nutrition. Patient B is in long-term care for dementia and has reached a point where she can no longer recognize her family and cannot form new memories but is generally happy. It is decided that she needs artificial nutrition to survive. Given the advanced directive, the surrogate decides not to provide artificial nutrition. However, Patient B continuously expresses that she is hungry and would like food or other care because she does not want to starve to death.

In this case, there is little intuition that Patient A has been harmed by his surrogate's decision. Patient A was not forced to remain alive in a state he previously expressed as incompatible with the type of life he wished to lead. However, despite advanced directives being correctly and strictly applied in this case, it seems hard not to sympathize with Patient B. She cannot comprehend that her past self chose to withdraw food from her current hungry self. So why do patients make decisions which lead to such dramatic scenarios? Dresser argues it lies in a lack of information because it is difficult for patients to imagine their worldview with impaired cognition (Dresser 2020 80). Instead, I believe what many people imagine a form of locked-in syndrome where their current mental system is trapped in a disabled body. They equate their current ability for cognition with their current value of life. In many cases, people with dementia are content with their current level of cognition and do not continuously feel distressed about their condition (Dresser 2020 80). According to geriatric ethicist Crees Hertogh, “people with dementia often come to terms with the consequences of their disease and adapt to the situation of dementia” (Hertogh 101). This idea is reflected in psychological literature (de Boer 1021). Dresser suggests that by considering advanced directives not only as a list of commands for care, but also as a more general expression of what that patient believes it is to die well, it is more respectful to the autonomy of that person not to impose upon them harmful treatment which “den[ies] patients with dementia the opportunity to receive care consistent with their contemporaneous interests” (Dresser 2020 86).

For this paper, I do not intend to discredit the overall effectiveness of advanced directives in expressing autonomous desires. Even when you allow for the theoretical limits Dresser presents, a problem still arises. Unlike cases where there is a clear break in a patient’s ability to express her wishes, dementia can cause patients to express current wishes which do not always seem intuitively worthy of dismissal. Dresser provides a strong epistemic argument against advanced directives. The nature of disability can significantly contribute to a patient’s inability to accurately express their wishes. Often, when the patient is faced with the challenges they once viewed as incompatible with life, they find themselves content and even happy (Dresser 2020 80). Though Dresser presents approaches such as education and social awareness, I question whether these epistemic issues are ever solvable. Perhaps we can never truly predict our future wishes. If this were true, it may then follow that advance directives are so fundamentally flawed in their ability to accurately represent medical wishes that they should be widely disregarded in medical decision making. I believe this is an overstep and that medical professionals should still respect the wishes expressed in advanced directives. Though there are problems with this method, it is still the most accurate prediction of a patient's wishes. Patients generally have the most self-knowledge and can therefore make assessments about what is good for their own bodies. Perhaps there are more effective ways to facilitate the decision-making process, but I do not believe a physician could make a more accurate prediction for a competent adult. These prejudices are pervasive even among medical professionals. It is a reason to encourage education, not discount autonomy.

Despite the limitations of advance directives to present medical wishes accurately, they likely remain the most accurate avenue for developing medical treatment standards. Patient B at Time 1 still holds the most knowledge about Patient B at Time 2, even if their knowledge at Time 1 is likely inaccurate. The ideas that Dresser presents are incongruent with how we treat patients in all other aspects of their lives. In general, respect for autonomy protects individuals who make decisions without a full understanding of the consequences of those decisions, even if those decisions go against generally accepted social norms. For example, we allow 18 year-olds to marry, even when it seems intuitive that both parties involved on some level cannot understand the possible consequences. From a neurological perspective, a dramatically underdeveloped frontal cortex inhibits logical decision making and increases reactivity dramatically in 18 year-olds (Hartley 108). Despite this intuition, it seems injurious to prevent individuals from making these decisions. Since it is injurious to prevent someone from making an autonomous decision, it is therefore injurious to prevent someone from making what we believe to be a 'bad' or ill-informed autonomous decision. We cannot reject advance directives on the grounds that non-disabled people make what we view as bad or ill-informed decisions for themselves. Though Dresser's argument is strong, I start from an assumption that advance directives should carry substantial weight in informing treatment decisions. This is discussed further in Section 2.1.

The bias Dresser presents weighs heavily on discussions of dementia, even if we accept that advance directives are viable decision-making tools. Able-bodied people regularly underestimate the quality of life of disabled people (Campbell). They undervalue the lived experiences of people with disabilities, citing their testimonial expressions of quality of life as less accurate, leading to inaccurate judgement about quality of life and value of life (Reynolds 60). This prompts many discussions of disability to falsely conflate the value in a life and the value of a life. The value in a life refers to the amount of good in that life, there will always be an innate value of that life, regardless of the bad that may come. The value of a life is the value that life holds, in comparison to the value of other lives. Many suggest that disability lowers the value of a life. A patient with dementia's life has the same innate worth as another's life. Many people view the life of people with dementia as having dramatically less worth in that life, which in turn decreases the value of that life (Reynolds 60). The quality of the things in that life are so low that the value of that life decreases. Similarly, Taylor argues that discussions of disabilities often equate the idea of a life worth living "to the prevailing social regard of the disabled body as questionably human, as aberrant, abhorrent, as an unfortunate existence" (Taylor para. 2). This is evident in public policy that repeatedly refuses equal services to disabled people (Taylor para. 3). Not only does this skewed view of a life worth living influence patients advance directive writing, but it also influences the way we conceptualize the treatment of disabled people and the value of their experiences.

In contrast with philosophically defining personhood centering rationality, independence, and competence that currently inform theories about moral status, Taylor views defining personhood as a more adjustable endeavor (Carlson 1) (Taylor para. 23). An effort to define personhood should be flexible and accommodating. Taylor reframes personhood away from the idea that an achievement of personhood informs the level of respect for bodily autonomy and self-determination (Taylor para. 16). Defining personhood should center on the moral status of those who these theories of rationality determine are not people, as opposed to strictly attempting to categorize people into a person non-person binary (Taylor para. 15). I believe this binary comes from an all or nothing view of personhood. Either a human fulfills certain standards and gains moral personhood, or they do not. This idea is especially important in a discussion of the treatment of patients with dementia. It centers on the importance of treating even severe patients with dementia with equal respect and moral status, regardless of whether they are viewed as acquiring the same moral status that personhood grants. In cases where patients with dementia express wishes for care, it is vital to acknowledge that Taylor's theories on the influence of socially constructed norms of cognitive ability may have undue influence on how these wishes are perceived. Because of this tendency to believe the lives of disabled people are worse than they are, we should exercise caution in assessing whether patients with dementia can make viable decisions for themselves (Campbell). Rather than asking whether patients with dementia are capable or smart enough to make decisions for themselves, it is more constructive to focus on whether the patient’s present wishes align with what is best for that patient.

When Ms. Taylor looks in the mirror, she does not see herself in the reflection. She fails the simplest nonverbal tests for self-awareness, the ability to attribute images in a reflection to self (Sofia). However, she is living an engaging life with friends and family, where she can understand and respond much like ‘Ms. Taylor’ and others continue to perceive her as Ms. Taylor (Kleinfield). This paradox leads to questions of persistence which I expand upon in Section 1.2. Until now, I have been using terms like “self” quite freely. Clarifying these terms is critical to addressing the problem of advance directives and their effectiveness. Questioning the strength of the persistence of identity over time in patients with dementia undermines the reasonings for the strength of advance directives presented above. The medical, mental, and social conditions of dementia provide a substantial basis to question the persistence of personal identity over time in patients with dementia. Phenomenologically, the entanglement of self with memory is complicated, and exactly how self persists in dementia remains unclear.

Section 2 – Prior expressed articulation and personal identity in dementia cases

Family and friends of patients with dementia often express that they have somehow lost themselves (Brodaty 217). They are a shell of their former self, a body with no mind. Their individuality is lost, a capacity for expression of self which has been devastated by a loss of memory and control. These motifs of loss are tied to the idea that a loss of one's ability to express autonomy is in some form a loss of self. Before discussing self and continuity in dementia cases, we must first establish why autonomy is important at all, and why is it so relevant in these cases.

Section 2.1 - Autonomy in non-dementia cases

Autonomy, defined as the right of a capacitated individual to have control over their body and mind, is the ultimate decision-making power in US medical care. Because a person's life plan and body belong to them, they should have the ultimate say in what is done to their body. We have a personal sphere of authority over actions done to us (Kant 17). This is a traditional Kantian view of autonomy, which defines autonomy as the ability to rationally consider choices aligned with a life plan "without direction from another" (Kant 17). Respecting a patient's right to non-interreference follows from a respect for their right to autonomy. The patient has the most knowledge of their personal values and therefore can make the most accurate medical decisions based on these values, even if the decisions are counterintuitive to the rational best interest standard (Feinberg 58). Autonomy is the overarching medical value because it is the way which patients qualify how other medical values, such as beneficence and non-malevolence, affect them (Post 18). These decisions weight because patients make medical decisions on the nature of beneficence or harm against the background of their personhood. Patients analyze different factors of what they believe to be good for them and apply it to their goals, wants and needs. This weight of autonomy prevents doctors from disrespecting an individual's personhood by making medical decisions that counteract a patient's self-developed best interest standards (Post 26). Outside of extenuating circumstances, we hold others to a high degree of responsibility for the effects of their actions based on an assumption that their autonomous actions are their own and therefore so are the effects. We expect 40 year-olds to pay off student loans from their teens and marriages remain binding regardless of time passed. Both student loans and marriage are binding on the assumption that you made an autonomous decision to engage in this type of agreement. These both require a stringent view of responsibility. To hold these to such a binding standard displays the immutable power of autonomy. Autonomy allows us to make decisions, even poor decisions, because of our self-ownership.

Autonomy is often central in discussions of dementia, as its loss is a defining medical factor in these cases. Because of the heavy consequences of treatment decisions, high standards for what autonomous decisions consist of are required. Yet, quantifying acceptable expressions of autonomy is a complicated endeavor (Post 24). Before discussing incapacitated patients, understanding what makes a patient capacitated helps define the line where patients no longer have direct personal autonomy and when doctors must supplement their decision-making process. Current medical standards define sufficient expressions of autonomy as the ability to provide informed consent. Informed consent sets three conditions (Post 19). First, capacitated patients must have a set of values to apply to medical decision-making which can be ascertained through consistent decision-making over time or explicit expression. Second, capacitated patients must be able to understand and process medical information and weigh the benefits and burdens of this information by applying their values to treatment decisions. Finally, capacitated patients must be able to communicate these decisions to their care team (Post 19). In cases of dementia, it is widely held that severe patients are unable to meet these necessary conditions and are therefore unable to provide the necessary informed consent to express autonomous wishes in medical decision making (Post 26).

A respect for prior explicit articulation follows from a respect for autonomy as the overriding factor for all other medical values. When a patient becomes incapacitated, doctors follow levels of decision-making: first prior expressed articulation, then substituted judgment, and finally the best interest standard. At a time when the patient was capacitated, they clearly stated their choices for medical care in case they were to become incapacitated (Post 26). This can take the form of a written document such as a living will or an explicitly recounted prior conversation. In practice, patients often express prior articulation by writing advance directives that legally document their personal values and preferences for medical care (Post 354). Doctors and surrogate decision makers have an obligation to respect prior explicit articulation because it is assumed that a patient’s expression is an accurate expression of the way which the patient wishes all other medical values to be applied to her. An overall respect for autonomy is the driving force behind the power which prior articulations have in making decisions for incapacitated people (Post 354). Their position at the first line of decision-making displays how this expression of a patient’s wishes is more vital than other processes which promote beneficence and non-malevolence. However, these prior expressed articulations do not have overriding power. Consider the case of a devout Jehovah’s witness, who holds a fundamental belief that Christians should not accept blood transfusions based on Biblical scripture and for him to accept a transfusion would be disrespecting his God. He has previously articulated in writing that he does not want, under any circumstances, to receive a blood transfusion. However, when the moment comes, and he experiences clarity in the face of certain death, he begs for a transfusion. In this case, it does not seem appropriate to refuse his current expressions of autonomy on the grounds of his past wishes (Dworkin 227). Current expressed medical values, if deemed appropriately informed and consensual, override a past expression of self. I have not yet argued whether it is possible for patients with dementia to currently express autonomy, but because of the strong way autonomy is valued, many medical decisions are made based on prior articulation in these cases.

As it stands now, most patients with dementia clearly fail to meet the current standards of informed consent. Patients with dementia can struggle to express themselves accurately as their ability to form coherent thoughts and verbalize those thoughts is often compromised (Post 127). In addition, they can lack an ability to understand or process medical information which is already highly complicated for fully capacitated patients.

The above arguments show we have strong obligations to honor past expressed autonomy and that they are vital aspects of medical decision making. However, much of the reasoning set out above relies on the idea that prior expressions of autonomy are important because they are one's own wishes. This presupposes that these prior expressions are made by the same self and are therefore centrally relevant to the well-being of that current, but same, self. The idea that patients with dementia have lost themselves seems to contradict this assumption, as it suggests some form of loss in the dominion of the past self over the present person. We must ask if obligations to past expressed autonomy based on an assumption of continuity of self significantly present in dementia cases.

Section 2.2 – Transformative experience theory of personal identity and memory loss

Persistence of personal identity is exceedingly complicated even in non-dementia cases. First, I will consider theories which suggest that the characteristics of dementia constitute a full break in the persistence of personal identity, as presented by Rebecca Dresser. Next, I will consider theories aligned with the views of Derik Parfit that suggest a partial or degreed loss of persistence. Finally, I will consider the argument of Ronald Dworkin, who suggests no significant loss of persistence occurs in dementia cases[2].

Memory is not the only important facet of identity. Some theories that argue a full loss of persistence is predicated on some level of physiological alterations which change the state of a person. Through this change, they become metaphysically distinct from what was previously considered to be a continuous self. Rebecca Dresser, drawing from Hume and Bentham in her reductionist theory of self, presents a theory I will call transformative experience theory. She suggests that, if a patient were no longer able to recognize their previous preferences, they are a metaphysically distinct person. Dresser's argument parallels Hume's assertion that personal identity is a mistake, and we are only a collection of perceptions experienced in rapid succession (Hume 131). Dementia could "produce a new person," who connection to their past physical being is "no stronger than that between you and me" (Dresser 1995 7). Dresser asserts there are significant weaknesses in the way we consider personal identity to infallibly exist through the same body over time.

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[2] I earlier distinguished between early, middle, and late stages of dementia. This distinction is notable in questions of personal identity. Since the cognitive ability of those with dementia can vary so widely over the course of a diagnosis, I plan to mainly discuss symptoms associated with middle- to late-stage dementia cases in this section. Symptoms would include significant and widespread loss to long-term memory, an inability to form new memories, and struggles with accurate communication.

Though Dresser does not provide substantiation for this claim, I see one supporting argument as follows. Extreme trauma can drastically alter our physical and mental state, and subsequently affect our ability to understand and articulate our “self.” Extreme trauma, such as the memory loss that is characteristic of dementia, can drastically change and alter our perception of self. This is derived from a view of the metaphysical self as comprised not of bodily continuity, but rather of personal identity, memory, character, and an acknowledgement of self-continuity. Changes to these characteristics can be so significant that a person is no longer the same self. Autonomy is derived from a self-endowed power of determination that requires a degree of self-knowledge. If a person were no longer the same self, we may have a weakened obligation to honor previously expressed interests. Since autonomy is integral to self, once the self has changed, the autonomous interests of past selves become less relevant.

I struggle with the implications of this argument. A transformative experience theory of persistence of personal identity must account for what form and to what degree psychological changes must occur to justify a transformative experience. Consider the example of teenage marriage given earlier. Is the psychological change from ages 18 to 30 significant enough to warrant a break in persistence? Certainly, the physical makeup of the brain, personality, self-view has all changed, yet these drastic changes do not seem to count as transformative. We do not attribute a loss of persistence to the process of development in young adulthood. Socially, we would never refer to the married 30-year-old as a different person than they were at 18. I think this problem of defining transformation disrupts the coherence of this theory. While a transformative experience could hypothetically disrupt a person's self to the point that they have become a completely different person, there is no coherent way in which this could be determined. If we accept that this theory as true, it is difficult for the theory to account for how personal identity and continuity exist over time. It is unclear how much of one’s personal identity and continuity must remain intact for the self to remain intact over time.

Section 2.3 – Parfitian theories of personal identity and memory loss

Not all theories of persistence are so dramatic. Some theorists posit a form of partial or degreed continuity of personhood. Derek Parfit’s work is contrary to a more traditional view of personal identity as an individual being a single continuous entity that exists through time. This traditional view asserts that a person remains the same throughout their lifetime, despite any drastic physical or psychological changes (Parfit 219). Parfit's theory challenges this view of continuous personal identity, claiming that personal identity is formed by psychological connectedness to past selves. Parfit uses a principle of identity relation to claim that the relationship between a person at one point in time and the same person at another point in time is not connected by continuous physical identity (Parfit 245). Rather, it is the experience of psychological sameness, not how individuals personally identify, which forms this relationship of continuity overtime (Parfit 282). A series of psychological states or events that connects the first person to the second person and this connection allows for those two people to be considered a continuous person (Parfit 289). For example, you and an identical copy of yourself both have the same claim two continuity. This is because you both have a psychological connection between you (as one person) and the current beings (two people). His argument questions a more solidified view of self which is commonly held (Parfit 219). Continuity of personal identity and self over time is not stable, the level of psychological continuity can fluctuate and therefore so can a connection to a past self (Parfit

290). This has clear implications for patients with dementia. Many patients with dementia experience a degreed level of continuity, which often fluctuates based on time of day or medical status (Khachiyants 275). Some patients experience periods of lucidity where they can recall their psychological connectedness to their past self or a past life but only for temporary time periods (Khachiyants 275).

Here, Parfit's concept of degrees of continuity becomes particularly relevant. Parfit calls for an addition of nuance to ideas such as morality or personal identity. When discussing personal identity, an all-or-nothing view of continuity is not sufficient. Instead, Parfit claims that, based on a degree of psychological continuity and connectedness, we can have stronger or weaker degrees of personal identity between our past and present self (Parfit 298). Parfit asserts that traditional views do not encompass the complexity which human connectedness and human morality present (Parfit 299). For patients with dementia, this means that they may experience stronger degrees of continuity of personal identity at times when they are able to remember their past life. It also means that at some points, when they are unable to recall any connection, their continuity is functionally weak enough that they have become a different person.

Unlike Dresser's view Parfit's approach does not rest on the idea that once personal continuity is lost, it can never be regained. Patients with dementia can have strong continuity in the morning and weak continuity in the afternoon. I believe this view is more consistent with the actual symptoms of dementia. It allows for a flexibility of interpretation based on the patient's psychological fluctuations. Patients who are experiencing a weak degree of personal continuity may make decisions that have no connection with their past self. They are only making decisions for their current self. That past self does not exist in the chain of personal identity. Parfit’s theory also does not require a strict memory-based psychological continuity (Parfit 308). For example, a patient may forget their own name and still hold some connection in the form of continuity. A patient may display continuous moral values and beliefs or emotional attachments to loved ones even if they cannot explain these attachments in the context of their current life. I believe this more accurately reflects the way that patients with dementia function. Parfit's theory suggests that patients with dementia experience a degree of loss of persistence as they lose a psychological continuity with their past selves. This partial loss of persistence is sufficient to warrant questioning of the applicability of advance directives and prior expressed articulation in decision making.

Section 2.4 - Counter theories of personal identity and memory loss

In Ronald Dworkin’s *Life’s Dominion*, he argues for the use of advanced directives in dementia care based in part on a respect for autonomy. Dworkin presents what I would label as a global desire fulfillment theory of well-being, in which “death is special, a peculiarly significant event in the narrative of our lives” (Dworkin 209). The global desire fulfillment theory of well-being argues that an individual's well-being is determined by the degree to which their desires are satisfied or fulfilled (Heathwood 135). This theory emphasizes the importance of desires in determining an individual's overall sense of well-being. It argues that desires are the central feature of well-being, and that the fulfillment of desires is what ultimately contributes to a person's overall sense of satisfaction with their life (Dworkin 224).

In *Life’s Dominion*, Ronald Dworkin distinguishes between experiential and critical interests (Dworkin 224). In advance directives, patients express critical decisions that align with their whole person as opposed to experiential interests which arise from their current situation (Dworkin 225). This is reminiscent of David Velleman’s theory of well-being

(Velleman 49), in which he asserts an action’s influence on the well-being of a person is not only measured by the impact on that person's well-being at that specific moment. It's value to well-being is also measured by that action’s influence within the context of the story of that person's life (Velleman 53). Actions can be important in the moment, but they can also fulfill particularly important goals or wishes in that person's life. The importance of personal autonomy and agency is central to Velleman’s theory of well-being. An individual must have the autonomy in order to act in a manner that maximizes their well-being in relationship to their life plan. This parallels Dworkin’s distinction between critical and experiential desires. Applying Velleman’s theory to Dworkin, critical desires are desires which impact one's life, not only because they bring momentary well-being, but because they fit within the story of one's life. Our well-being is not determined by external factors such as wealth or health, but rather by our own internal motivations and desires. Dworkin believes that, in the formation of the whole person, the worth of certain desires is proportional to the way they exist within that person's entire life (Dworkin 199).

A whole person is the accumulation of critical interests spanning from one edge of life to the other. The purpose of advance directives is to allow the patient to receive care aligning with what they view as the critical goals or purpose of their life (Post 26). Dworkin suggests that decisions are in our best interest if they follow the narrative of our life plan and should not only be judged by the momentary well-being they bring about. The way we die is one of our most important decisions, and we must highly respect the autonomous decisions made about the circumstance of our death. It is in the best interest of both patient’s autonomy and their well-being to take their past expressed wishes seriously (Dworkin 228). This argument presupposes a certain amount of persistence, which Dworkin argues is enough to justify the continued use of advanced directives. Before discussing why death is so important to self, it is important to establish what self remains.

Though not explicitly defined in *Life's Dominion*, Dworkin's views on personal identity can be extrapolated from his narrative view of the self. Dworkin, like Parfit, rejects the view of personal identity as a possession of the individual (Dworkin 199). Individuals do not own their personal identity over the course of their life. It is not objectively attached to that individual no matter the circumstances. I believe Dworkin's view is more subjective, seeing personal identity as formed by a person's desires and memories which can change over time. This narrative view is formed by self-reflection. An individual takes this continuity of beliefs and memories, and forms critical desires on how their decisions fit into this narrative they have created for what it means to live a good life (Dworkin 199). An individual may form experiential desires which do not always fit into this narrative plan. Only critical desires based on self-reflection should count as viable medical decision-making tools. Dworkin sees experiential desires as often deviating from what is truly good for that individual (Dworkin 209).

Dworkin does not believe that patients with dementia experience continuous personal identity over time. Dworkin differs from Parfit in his belief that this lack of continuity should not affect treatment decisions in cases of dementia (Dworkin 209). To Dworkin, personal identity is important because patients with dementia lose the ability to form critical desires based on their personal identity. Because they have lost this ability to connect with personal identity, patients with dementia should no longer be allowed to make decisions about their care. They have lost the ability to form critical desires (Dworkin 209). In order to form critical desires, a person must be able to consider how those desires fit into the narrative version of that person's own life (Dworkin 199). Patients with dementia who have lost continuity of personal identity cannot do that.

Section 3 – Decision making capacity in patients with dementia

Even in cases where a patient's loss of persistence warrants a weakened reliance on their advanced directive, there still remains the question of how to elicit medical wishes from patients with dementia. As outlined in Section 2.1, it would be nearly impossible for a patient with substantial dementia to meet the current standards of informed consent (Post 19). The standards of informed consent require that a patient have the capacity to understand the medical information, make decisions voluntarily and without undue influence, be able to comprehend the information provided, be legally competent, and be able to give their express informed consent.

Patients with dementia often cannot fulfill these standards for informed as many of them do not have the capacity to understand complex medical information and weigh the pros and cons of their actions (Post 27). I believe there are some cases where practitioners should override the past expressed wishes of a patient with dementia in favor of their current wishes. For example, patients with dementia often become confused or distressed by activities that seem mundane, such as eating or showering (Whall 217). However, their difficulty eating does not necessarily reflect a genuine desire to stop receiving food. It is driven by fear and confusion and is not an expression of a desire for care. Not every current wish will be an accurate depiction of a dementia patient's goals for care. We must further examine the symptoms of dementia and how those symptoms affect patients with dementia. We can then elicit some standards for how decision-making capacity exists in patients with dementia. Consider the following example:

> In her thirties, Mrs. Z became heavily addicted to opioids but eventually recovered. She continued to work as an addiction counselor well into her 70s. She is now 80 years old and was diagnosed with Alzheimer's three years ago. She has developed significant symptoms. She has explicitly expressed in her advance directive that she

> wishes never to receive opioids, having built her identity fundamentally around her recovery and she wishes to die peacefully. However, alongside dementia, she has lost a significant degree of muscle control and has developed painful bedsores due to lack of movement. All other pain management techniques have failed. She constantly requests stronger pain relief by grabbing the nurse’s arm and moaning “more, please, more”. Her physician offers oxycodone, but her husband is concerned she would not want it.

Section 3.1 - Expressing critical desires in patients with dementia

To dispute Dworkins’ argument that patients with dementia lack the capacity to form critical desires, we must first establish whether dementia patients have a capacity to value at all. The ability to apply values to a set of treatment options and to be directed by these options is central to informed consent. In “Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value,” Agnieszka Jaworska attempts to set some standards in eliciting a patient’s capacity to value. Jaworska’s central argument focuses on residual senses of agency in patients with dementia. Many patients with dementia have lost the ability to make fully competent decisions for themselves or to accurately communicate their wishes for care. However, their agency and capacity to value has not been completely removed. Patients with dementia “still possess a residual sense of agency that can be expressed in their behavior and that we should respect this residual sense of agency even when they are unable to make explicit decisions" (Jaworska 3).

The traditional sense of agency as an ability to rationally consider certain actions is too narrow of a view when it comes to patients with dementia. The capacity for agency and the capacity to value are multifaceted and complex. This complexity is not captured in the current standards for informed consent. These standards rely exclusively on a patient's ability for rational thought and subsequently ignore the realities of care in patients with dementia. As previously discussed, Parfit suggests that personal identity can express itself as a matter of degree and that a patient may have a capacity to value more accurately at certain times based on their experience of continuity. Jaworska highlights the importance of recognizing that patients with dementia still possess a residual sense of agency and capacity to value, even if they cannot express it in the traditional sense.

This view is evident in Mrs. Z's behavior, as she is still able to communicate her pain and her desire for relief through nonverbal cues and gestures. Blindly following Mrs. Z’s prior expressed wishes does not fully capture the multifaceted and complex nature of agency and capacity to value in patients with dementia. Her agency has adapted to her current situation to form new values. Using Parfit's suggestion that personal identity can express itself as a matter of degree, Mrs. Z may still have a capacity to value certain things, even if she no longer connects with the facet of her identity which valued sobriety. It may be appropriate to fulfill her current wishes and provide the care she is requesting. Mrs. Z’s case displays how preferences can adapt to form new values based on the situation. Because of her medical trajectory, the risk that Mrs. Z develops an opioid addiction again is very low and ultimately inconsequential to her health. The value which once drove her life is no longer applicable in this situation and it is reasonable to assume that a new value supersedes it.

This residual agency may not express itself as explicitly as it would in a non-dementia patient. Jaworska suggests that by observing nonverbal cues, habits, physical actions, and other forms of communication, caregivers can determine a capacity to value certain medical decisions over others. For example, a patient with dementia can express a preference for certain foods through their actions, such as pushing the tray away, even if they no longer have the verbally communicate their dislike to a caregiver. Jaworska argues that patients with dementia are constantly valuing certain actions (Jaworska 7). In my opinion, discrediting the level of cognition in patients with dementia because they can no longer express their values in traditional ways overlooks the fact that they can still exhibit cognitive abilities that differ from those of non-patients with dementia.

Though patients with dementia may not express a capacity to form values in a traditionally rational way, their expressions should not be ignored. These values are still legitimate expressions of what is good for that patient. They are still using, within the bounds of their current cognition, an adapted ability to weigh certain actions to form values. This remains faithful to the overarching purpose of an advance directive, and to autonomy in general, which is to do good to the patient and ensure that no unwanted care is forced upon them. When Mrs. Z previously expressed her wishes for care, she refused opioids because it was part of her core tenet not to relapse into addiction. It is still faithful to her advanced directive to provide opioids to let her die peacefully. The aspect of herself which could have relapsed into addiction no longer exists.

Section 3.2 – The non-alienness principle

Having established a patient's ability to value, we can now accept that some patients appreciate that certain medical decisions are good for them. Dworkin believes that the autonomous critical desires of the past person should supersede the experiential wishes of the current person. However, this leads to an unacceptable conclusion. Cases arise where the patient is alienated from the good. This means that the patient fails to experience the good as good for them (Hawkins 526).

In the prior example, Mrs. Z's is alienated from her original desire to not use pain medication. She cannot in any sense recognize that her past self expressed a critical desire that not using pain medication was good for her. Dworkin's argument claims that what is good for Mrs. Z is to stay faithful to her advance directive. According to Dworkin, she fails to experience what is good for her as good for her. In this case, she experiences it as actively negative. Jennifer Hawkins' "Well-being, Time, and Dementia" is a response to this exact problem in Dworkin's argument. If patients with dementia can accept that their current decisions are in some way good for them based on the capacity to value, should those decisions then be taken more seriously? As outline below, I believe Hawkins' non-alienness principle can be used to show that these current desires are less alienated from what is good than a past desire might be. Though Hawkins does not completely discount Dworkin's argument of critical interests, she suggests that this idea is no longer relevant given experiences of patients with dementia (Hawkins 528). Though many patients with dementia lose the context needed to form critical desires in relation to their own life narrative, they can still form critical desires. However, these new desires have serve a new purpose, which is to maintain a sense of self despite losses to function (Hawkins 518).

According to Hawkins, the way in which patients with dementia experience self and continuity can be understood through what she defines as the non-alienness principle. It is a non-alienable aspect of a person's well-being to be able to experience their life meaningfully and continuously (Hawkins 526). What is good for a person is for their experiences and personal identity to remain relatively stable over time, without being disrupted or altered in ways that are not in line with their values and preferences (Hawkins 526). Mrs. Z is distressed by the lack of pain medication because her current personal identity and experiences create a value under which she desires pain medication. She experiences this as continuity of her life, despite having had another set of values to which she can no longer psychologically connect.

While critical desires can be central to a person's past life, they can become distressing because that patient does not experience them as meaningful or continuous with their current identity. Losing the ability to experience control during dementia can result in a loss of the patient’s sense of self and personhood (Hawkins 518). A caregiver should help patients maintain a sense of continuity and create an environment where their experiences support meaningful continuity. Their actions and care must be driven by a desire to uplift the patient’s sense of continuity. The non-alienness principle stipulates that “a person’s good must enter her experience, if it does, in a positive way” (Hawkins 526). In the context of dementia, a person's good must be experienced by that person as good. We must implement care which the patient experiences as good. Mrs. Z has experienced so much pain that she does not experience a faithfulness to a past self as good. It may be extremely confusing to her sense of continuity to try and explain why she is not being given the pain and medicine she desires. Following from Hawkins’ argument, I believe Mrs. Z should be given pain medication because she fails to experience her advance directive as in any way good for her. Based on Jaworska’s argument, she has made a critical desire, based on a limited capacity to value, about wanting to receive stronger pain medication. I believe this fulfills what Hawkins sees as an unalienable aspect of well-being: Mrs. Z can experience the good as more meaningful because it connects with her current experience of time and continuity.

Section 4 – Conclusions

Accepting that patients with dementia have critical desires and therefore should have a meaningly say in their medical processes is not without risk. Advance directives exist for a very important reason. They preserve the wishes of who that person once was and still is to some extent. Questioning written directives introduces another set of issues concerning the accuracy and reliability of ascertain a patient with dementia's current wishes. It is hard to mess up the wishes of an advanced directive, as it is explicit and legally binding. But trying to elicit values from a person who cannot communicate them is exceedingly complicated. Jaworska and Hawkins both suggest some ideas on how to do this, such as considering nonverbal cues and observing behaviors. Inevitably these systems will not be perfect. Perhaps allowing a patient to experience happiness in their last days is more important than the possible mistake made in ascertaining they are true critical desire.

> Mr. F has been an orthodox Jew his entire life and has always subscribed to its central tenet, the sacredness of life and the imperative to preserve it above all else. Two years ago, he was diagnosed with Alzheimer's disease and has significant dementia. Now that he is hospitalized with pneumonia, Mr. F's doctors are disturbed by a request that he has been making with increasing frequency. He tells them he has nothing left to live for and that he wants to die, explicitly rejecting the medication necessary to treat his pneumonia. This signifies a rejection of his previous values, and doctors question whether he can make rational decisions in his condition. Mr. F has no surrogate decision maker.

Section 4.1 – Possible risks of disregarding advance directives in dementia cases

Alzheimer's disease has no cure and patients with this condition will never fully recover their mental capacity. As a result, patients with dementia will likely never be able to fully understand or comprehend if their advance directive is being violated. This raises significant ethical questions about whether it is appropriate to allow patients with dementia to have a say in their medical processes, given that they may not fully understand the implications of their decisions. In the moment, Mr. F does not desire to continue living. However, allowing him to die has extremely serious implications for his religious beliefs and a a failure to uphold them. Despite these challenges, I still believe that patients with dementia have critical desires and should be allowed to participate in their care as much as possible. This participation can preserve the person's current and ongoing existence, while also respecting their previous wishes and desires.

By taking a thoughtful and nuanced approach to medical decision-making for patients with dementia, we can ensure that we are doing our best to honor their wishes and preserve their dignity. Ultimately, the philosophical basis for allowing these decisions should be indriven by what's in the patient's best interest, even if they are not fully aware of the decisions. For example, though physicians are aware of Mr. F's prior desires to receive lifesaving care, it is perhaps more faithful to Mr. F's desires to allow him to die on his own terms. Despite his faith, the current Mr. F has no connection or religious reason to die in what he believes to be a painful and lonely manner. While we should not ignore his past religious beliefs regarding lifesaving care, there is perhaps a stronger reason to ensure the current Mr. F is not forced to live a life he deems incompatible with his current desires.

4.2 – Further complications with advance directives

I have provided only a cursory examination of the numerous issues that affect the care of dementia patients. There are innumerable other important considerations. For example, the solutions discussed above which rely on persistence are really asking to what degree the autonomy of a previous person should be respected. But personal autonomy is not all there is to patient ethics. If autonomy were not held to such a high standard, we might then question much of the current care standards that rely heavily on the idea of preserving past autonomy.

Patients with dementia are and will remain unaware that their past self has been ignored. I believe they are unlikely to realize their past autonomy has been overridden in favor of their current wishes.

Mr. F is unlikely to regret his religious transgression in death. This may lessen our haste to follow advance directives that transgress a patient’s autonomy. We have so far held that respecting autonomy were the main reason we continue to provide Mr. F with care he explicitly refuses. But without autonomy as a driving principle, we may have even stronger reason not to force care on him. There are other guiding principles such as non-maleficence (doing no harm) or beneficence (doing what is in the patient's best interests), that could lead us to conclude that forcing care on Mr. F is not appropriate. Before deciding to implement or restrict care against a patient’s wishes, it is important to carefully weigh the potential benefits and harms of any medical intervention, to consider the patient's values and preferences, and to assess any legal and ethical considerations. Mr. F’s application of his autonomy to respect his religious views becomes less important if maintaining autonomy were not central to his medical status. There are numerous other views which value alternate aspects of care which could drastically change the way decision making is discussed in dementia cases.

4.3 – Implications for dementia care

The complications of Mr. F’s case are not uncommon. At the intersection between personal autonomy and personal identify, cases like this force us to confront how degenerative memory disorders affect personhood. While Mr. F is clearly disconnected from his past values, much of what made him remains. Within him is the same body and mind who was dedicated to strict religious principles. But the mind which held these beliefs will never return. The degenerative characteristics of dementia have degraded his mind and a new mind with new values has adapted in its place.

As with many patients, there is not one all-encompassing answer to the question of what should be done in Mr. F's case. However, I do not believe that physicians should blindly follow an advance directive on the grounds that it is most faithful to the person Mr. F once was. We have significant reason, based on a wavering persistence of personal identity, to question whether his advance directive should be followed.

Those who question the strict use of advanced directives often offer some guidance on how these current wishes can be elicited. There have been several case studies which have taken these philosophical ideas into practice by offering a holistic treatment approach that considers factors such as a patient’s background, personal beliefs and values, and current situation (Whall) (Ljubič 126). These models often encourage a one-on-one connection between medical staff and patients with dementia. This makes it easier for those staff to elicit whether these new expressed wishes are the result of dementia-induced confusion or legitimate expressions of wants for care. However, a care model that fully addresses the complex issues presented above has yet to be proposed. The intricate relationship between memory and self in dementia highlights the need for further exploration and clarification of the concept of self and its persistence over time. Ultimately, understanding these concepts is crucial for providing compassionate and effective care for patients with dementia.

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