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TARGET ARTICLE



Cognitive Transformation, Dementia, and the Moral Weight of Advance Directives

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ABSTRACT

Dementia patients in the moderate-late stage of the disease can, and often do, express different preferences than they did at the onset of their condition. The received view in the philosophical literature argues that advance directives which prioritize the patient's preferences at onset ought to be given decisive moral weight in medical decision-making. Clinical practice, on the other hand, favors giving moral weight to the preferences expressed by dementia patients after onset. The purpose of this article is to show that the received view in the philosophical literature is inadequate and is out of touch with real clinical practice. I argue that having dementia is a cognitive transformative experience and that preference changes which result from this are legitimate and ought to be given moral weight in medical decision-making. This argument ought to encourage us to reduce our confidence in the moral weight of advance directives for dementia patients.

KEYWORDS

Advance directives;
neurodegenerative disease;
philosophy; moral theory;
health policy; end of
life issues

INTRODUCTION

In standard medical decision-making, patients are free to make their own choices regarding their treatment, so long as the patient in question is judged by medical professionals to have the requisite mental capacity to make an informed decision (Groll 2015).¹ When capacity is compromised by a condition such as late-stage dementia, the patient is judged to no longer have the ability to know what is in their best interests.² In such cases, the responsibility for the decision of how to act in the patient's best interests is left in the hands of medical professionals or family members. Making this decision is particularly problematic, even harrowing, in cases in which the patient's current preferences contradict their preferences as expressed in an advance directive. Advance directives are documents that allow individuals to set out directions and preferences for their future medical care, in the eventuality that they lose their decisional capacity (de Boer et al.

2010, 202).³ These documents have traditionally been conceived of as an effective means of extending an individual's autonomy from their current self, as an individual who has decisional capacity, onto their future self, who lacks it.

Advance directives currently have varying degrees of legal strength on a global scale (Vezzoni 2005). The strongest legal status for these kinds of documents can be found in countries such as the Netherlands, Belgium, Denmark, and the United States, where advance directives are legally binding on physicians (de Boer et al. 2010, 202–203). Meanwhile, countries such as Germany, Switzerland, and Norway give these documents “weak” legal status. In circumstances such as these, whilst advance directives are viewed as having some legal status, this status does not hold decisive moral weight in medical decision-making (de Boer et al. 2010, 203). Meanwhile, countries such as

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¹In medical contexts, determining decisional capacity is a part of every substantive interaction between a patient and their physician (Fellows 1998). Typically, determining decisional capacity involves a physician making an assessment of a patient's ability to express, make, and understand the consequences of, a particular decision. This assessment can also be done with regards to a specific task (Moye and Marson 2007, 3).

²Dementia has arbitrarily been divided into three dominant stages: early, mid-stage, and late-stage. Often these stages of the disease blur, but late-stage dementia is characterized by a severity of functional impairments, which cause the patient to require full-time care. In particular, the patient may find themselves easily disorientated, frustrated at their inability to do daily tasks such as clothing and washing themselves, and their perceptions may become distorted or blurred (Wells 1977, 5–7).

³The most common kinds of advance directives are treatment and proxy directives. The former specifies what treatment, if any, the individual would desire in the future, and the latter specifies another person who is empowered to make decisions on the patient's behalf. Whilst less common, advance directives can also be written for euthanasia (de Boer et al. 2010, 202).

Japan give advance directives no legal status at all (de Boer et al. 2010, 203).

The purpose of this article is to argue that the received view in the philosophical literature, which defends the strongest legal status of advance directives, is philosophically inadequate as well as out of touch with clinical practice. Clinicians show reluctance to implement an advance directive when it is in contrast with the well-being and current preferences of the dementia patient in question. Significantly, this is not simply the case in small sample of cases; both ethnographic and compliance studies indicate that clinicians have a “low opinion of the effectiveness of advance directives and are inclined not to follow treatment directives in case the content of the directive differs from, or is opposed to, their medical judgement” (de Boer et al. 2010, further evidenced by Vezzoni 2005 and The et al. 2002). This article offers a philosophical defence of current clinical practice, by arguing that preferences made after a transformative experience such as having dementia are legitimate and ought to be given moral weight in medical decision-making. As such preference changes are unpredictable, given the nature of transformative experience itself, they could not be fully considered by someone who is in a process of drawing up an advance directive.

The structure of the article is as follows. §2 will outline the received view regarding the moral weight of advance directives, which is developed by Ronald Dworkin, and has been subsequently defended by prominent scholars such as Jefferson McMahan (2003) and Govind Persad (2019). Dworkin’s account relies on the idea that a person’s critical interests show a degree of stability over time. I suggest that Dworkin’s account fails to consider cases of transformative experience, where a person’s preferences can change dramatically. I elaborate on this consideration, and fully expand on the notion of transformative experience, in §3. Here, I present the idea that undergoing a cognitive transformative experience such as dementia ought to mitigate the moral weight we assign to the patient’s advance directive. This section will also consider why cognitive transformative experiences differ in kind from other transformative experiences such as giving birth for the first time. §4 considers what upshot this has for the issue of advance directives. It is not a consequence of my account that persons shouldn’t be allowed to choose to give their advance directive significant moral weight if they so wish. Moreover, if a patient is aware of and has considered the implications of what I discuss in §3, and still wishes to give full moral weight to their directive,

then this is permissible on my view. My account should be viewed as an argument in favor of reducing one’s confidence in the effectiveness of advance directives and as an explanation as to why it is currently morally problematic to allow such documents decisive moral weight in medical decision-making. I conclude in §5 that preferences made after cognitive transformative experiences are legitimate. Clinician’s beliefs regarding the limitations of advance directives suggest that they already realize this; I suggest that philosophers need to do the same.

ADVANCE DIRECTIVES AND DEMENTIA: THE RECEIVED VIEW

The received view in the philosophical literature, put forward by Ronald Dworkin (1994), argues that advance directives ought to be given decisive moral weight in medical decision-making. Dworkin (1994, 219–235) claims that certain decisions, ones regarding the cessation and prolongation of life, ought to lie with individuals (Shiffrin 2015, 3). He argues that advance directives reflect an individual’s judgements about their own lives and, as such, should be given significant moral weight, even if they direct medical professionals to curtail the life at stake (Shiffrin 2015, 3). The following real-life case studies serve to illustrate the complexity of this issue.

The first case study involves a woman called Mrs Black (Sokolowski 2018, 45–83). At the age of eighty-five, Mrs Black received a diagnosis of mid-stage dementia. Due to the progression of her dementia, Mrs Black often struggled to recall the names and faces of family members. Nevertheless, she was noted by her nurses at the residential aged care facility she lived at as being an exceptionally happy woman. She took joy in her daily activities, particularly watching birds pass by through the window. Whilst in care, Mrs Black developed a serious bacterial infection. She had an advance directive stipulating that if she were ever to suffer an illness which resulted in her inability to recognize her family members, she would not wish to receive any medical treatment to prolong her life. Consequently, her son insisted that her advance directive be followed and so the directive was implemented. She died shortly after. The entire medical team report feeling “devastated”. Mrs Black’s nurse Lily surmised, “when Mrs Black wrote the advance directive, she probably did not consider the idea that she could have dementia and still enjoy a good quality of life” (Sokolowski 2018).

The second case is that of Mr White, who received his diagnosis of early-stage dementia at age sixty-five (Sokolowski 2018, 85–121). As the disease rapidly progressed, Mr White was put in residential care. Two months after being in care, he received a new diagnosis of having an inoperable brain tumor. After this diagnosis, both of his children convinced him to update his living will; at which time an advance directive was drawn up for his care, naming both of his children as attorneys for his personal care. Mr White's state declined rapidly after this. His physician explained to him, and his children, that without a feeding tube being inserted into his stomach, he would likely die soon, as a result of his inability to take food or water by mouth. Mr White gave inconsistent answers to his physician regarding the insertion of the feeding tube. His children also had different views on whether the tube should be inserted or not. His son referred to the fact that his advance directive stated for “no heroic measures” to be taken to save his life. His son cited this as evidence that his father would not wish to have the tube inserted. His daughter, on the other hand, stated both that she was unsure that her father had the requisite capacity to write the directive and that the statement “no heroic measures” was too vague to be interpreted as meaning her father wouldn't want the feeding tube. As a result, the physician decided to ask Mr White one last time regarding whether he wanted the tube inserted or not. Mr White expressed a wish for the tube and so it was inserted; contrary to his son's wishes and, according to his son, contrary to the instructions set out in his advance directive.

Dworkin presents two arguments as to why he believes advance directives ought to hold decisive moral weight in cases such of these: the argument from autonomy and the argument from beneficence. The argument from autonomy begins by acknowledging that competent adults have a right to autonomy, by which we mean a right to make decisions for themselves (Dworkin 1994, 222).^{4,5} Dworkin illustrates how much moral weight we give to this right, particularly in medical contexts, by referring to the example of a Jehovah's witness who has the right to refuse life-

saving blood transfusions because so doing is not in keeping with their religious convictions (Dworkin 1994, 222). Dworkin then asks: when is that right lost? Is the right lost, or compromised, in certain cases where individuals lack certain cognitive capacities?

In order to answer this question, Dworkin suggests that we need an account of why autonomy is so fundamentally important to us in the first place. He considers two such accounts: the evidentiary view of autonomy and the integrity view of autonomy. The evidentiary view maintains that we should respect decisions individuals make for themselves, even if they are objectively undesirable, because individuals are often the best judges of what is in their best interests. Dworkin points out that if we accept this view of autonomy, we should not extend the right of autonomy to the severely demented because such persons have lost the requisite mental capacities to truly know what is in their best interests (Dworkin 1994, 223). Nevertheless, Dworkin rejects the evidentiary view of autonomy as persuasive because it fails to explain when and why people have the right to autonomy. He asks us to imagine that we know someone who likes to smoke and enjoys doing so even though it harms their overall well-being. Dworkin states, “If we believe ... that respecting their autonomy means allowing them to act in this way, we cannot accept that the point of autonomy is to protect an agent's welfare” (Dworkin 1994, 223). As a result, Dworkin argues that we cannot think that the right to autonomy ought to be respected for this reason alone, as it is not clear that individuals are the best judges of what is in their best interests. Dworkin thus rejects this view as an adequate explanation of why autonomy is important to us.

Another explanation Dworkin considers is given by the integrity view of autonomy. This view postulates that autonomy is important because it “encourages and protects people's general capacity to lead their lives out of a distinctive sense of their own character” (Dworkin 1994, 224). According to this view of autonomy, people can, and often do, make choices which harm their welfare. Nonetheless, it follows from the integrity view of autonomy that it is still worthwhile to allow individuals to make these kinds of personal choices for themselves. According to this view, whether or not the severely demented have a right to autonomy hinges on the degree of their general capacity to lead a life out of a sense of their character (Dworkin 1994, 225). Dworkin gives us reason to think that it is unlikely that severely demented patients have such a capacity, as dementia patients in

⁴The right to autonomy in this context refers to the right an individual who has decisional capacity has to make decisions regarding their own medical care.

⁵Competency is a legal concept, which is typically informed by a physician's judgement of decisional capacity. Legal standards for determining competency vary, but such standards usually require that the patient is able to express a choice, to understand the relevant information in making a particular choice, to appreciate the medical consequences of their decision, and to be able to reason properly about their options (Applebaum 2007).

the moderate-late stage of the disease often have whimsical preferences which may well end up contradicting one another (Dworkin 1994, 225). As such, Dworkin argues that dementia patients who are in the latter stages of the disease have lost their right to autonomy because they have lost the mental capacities necessary for the attribution of the right to make sense (Shiffrin 2015, 4).

Dworkin concludes that patients with severe dementia have “no right that *any* decision be respected just out of concern for their autonomy” and that this is in accordance with either view of autonomy, integrity or evidentiary, we endorse (Dworkin 1994, 226). Dworkin then considers the question: what about a patient’s *precedent* autonomy? (Dworkin 1994, 226) He asks us to suppose that a dementia patient, called Margo, was competent in the past before developing dementia. In this time, Margo writes an advance directive which states that she should not receive life-saving treatment for any life-threatening illness she may contract (Dworkin 1994, 226). He states that if we accept the evidentiary view of autonomy, we wouldn’t be compelled to accept Margo’s instructions given that her preferences are likely completely changed in her new demented state. Nevertheless, Dworkin argues that if we accept the integrity view of autonomy, it follows that Margo’s past wishes should be respected because writing an advance directive is making exactly the kind of judgment that autonomy, according to the integrity view, most respects, “a judgement about the overall shape of the kind of life she wants to have led” (Dworkin 1994, 226). As Dworkin endorses this latter view, this is the position he ends up holding.

Dworkin then makes a second argument as to why advance directives should hold moral weight in cases of dementia: the argument from beneficence. Dworkin argues that even though the severely demented lack rights to autonomy, they retain a right to beneficence, the right that decisions be made in their best interests. He claims that despite this, it isn’t clear what follows from this right, or what the consequences of possessing this right are. To begin to answer the question as to what is in a dementia patient’s best interests, Dworkin draws a distinction between two forms of prudential interests—experiential and critical interests (Dworkin 1994, 229). Critical interests concern what is fundamentally important to the overall success of our lives. According to Dworkin, such interests are a distinct set of prudential concerns which, when fulfilled, genuinely make a person’s life better (Dworkin 1994, 202). Moreover, our critical interests reflect who

we are and what is fundamentally important to us and are convictions about what helps to make a life good on the whole (Dworkin 1994, 202). For instance, one could have a critical interest that one’s relationships are meaningful to them and so put a lot of effort in to maintaining them. These interests are contrasted with a different kind of prudential interest: experiential interests (Dworkin 1994, 226). Experiential interests are concerned with the quality of our own experiences and with pleasurable experiences, such as eating a delicious slice of chocolate cake.⁶

According to Dworkin, satisfying critical interests has priority over satisfying experiential interests. This is because the satisfaction of the former is essential to our well-being in a way the latter is not (Dworkin 1994, 230–232). Dworkin demonstrates this point by contrasting the importance of a critical interest, in this example, the critical interest of valuing your relationships with your children, “I do think my life would have been worse had I never understood the importance of being close to my children” with the effect of an experiential interest “My life is not a worse life to have lived—I have nothing to regret, less to take shame in—because I have suffered in the dentist’s chair” (Dworkin 1994, 201–202). Dworkin states that severely demented patients are:

ignorant of self—not as an amnesiac is, not simply because they cannot identify their pasts, but more fundamentally, because they have no sense of a whole life, a past joined to a future, that could be the object of any evaluation or concern as a whole. They cannot have projects or plans of the kind that leading a critical life requires. They therefore have no contemporary opinions about their own critical interests. (Dworkin 1994, 230)

Herein lies the reason why Dworkin thinks we should implement the advance directive of the severely demented patient to promote their best interests. In line with Dworkin’s conception that patients with severe dementia lack certain capacities, it follows that these patients lack the ability to have a sense of their own lives as extending over time and therefore

⁶We can make sense of this distinction if we are careful to pick the right examples. These examples typically contrast an important critical interest with a trivial experiential interest. My previous example of contrasting one’s meaningful relationships with one’s chocolate cake eating is an illustration of this. Given my example, it is reasonable to think that, in ordinary circumstances, one should favour pursuing meaningful relationships over one’s chocolate cake-eating and so critical interests are more important than experiential ones. Nevertheless, the persuasiveness of this distinction can lose credibility when we alter the experiential interest in question. For instance, imagine that we changed the example of the experiential interest to one where an individual experienced acute pain. It isn’t clear in this case that one would think more about one’s relationships than one’s chronic pain.

fail to engage with, or have contemporary opinions about, the critical interests they held as a person before getting dementia. As on Dworkin's account these interests matter most when considering a patient's best interests, we should look to, and adhere to, the critical interests they expressed in their advance directive(s), even if their contemporaneous pleas contradict their advance directive.

The argument from autonomy relies on us believing, like Dworkin does, that dementia patients in the moderate-late stage of the disease lack the mental capacities necessary to lead a life out of character. Dworkin seems to make this assumption based on thinking about dementia patients who lack stability of preferences. Whilst such dementia patients do exist, it is certainly misrepresentative of a large portion of moderate-late stage dementia patients who do show a degree of stability in their preferences, even though these preferences may have altered drastically from the preferences the patient showed at the onset of their disease. We cannot assume that because a dementia patient's preferences drastically change over the course of their illness that this is indicative of a degradation of their autonomy. It may well be, or it could be that such preference changes are the result of undergoing a transformative experience. As we cannot know either way, I argue that we ought to take seriously the preference changes a dementia patient experiences throughout the course of their illness and give them due moral weight. This argument will be developed in §3.

In a similar vein, the argument from beneficence relies on us believing that critical interests are the more important interests and that these interests show a degree of stability and resistance to change across time. I argue in §3 that transformative experiences are unique insofar as they have the power to radically alter our critical interests. If this is true, we cannot assume, as Dworkin does, that such interests will necessarily show a degree of stability across one's lifetime.

TRANSFORMATIVE EXPERIENCES

L.A. Paul's book *Transformative Experience* introduces the idea that some perspectives are epistemically inaccessible to us until we have experienced them (Paul 2016). For instance, a baby may not be able to know what chocolate ice-cream tastes like until they have eaten it (Paul 2016, 14). Likewise, adults who wish to have children will not know what it is like to have children until they have them (Paul 2016, 15–16).

These two experiences, whilst both being transformative in some sense, are transformative in different ways. The former, the baby's ice-cream tasting, is epistemically transformative insofar as the baby's experience of eating the ice-cream for the first time will give them some new information in virtue of having the experience (Paul 2016, 14). The latter, choosing to have children, is personally transformative insofar as once one becomes a parent, there is a sense in which your whole being changes; the way you experience yourself changes and so too may your critical interests. Importantly, these two kinds of transformative experience are not mutually exclusive; indeed, Paul's book primarily focuses on experiences which involve both aspects (Paul 2016, 17).

Paul gives two different, but equally important, examples of kinds of experiences which involve both epistemic and personal transformative elements. The first is as follows. Imagine you are presented with the opportunity to become a vampire. With one bite, you will be changed into "an elegant and fabulous creature of the night" (Paul 2016, 2). Unsurprisingly, "as a member of the undead, your life will be completely different" (Paul 2016, 2). However, we cannot know exactly how this experience will feel for us until we experience it because "you cannot compare the character of the lived experience of what it is like to be you ... to the character of the lived experience of what it would be like to be a vampire" (Paul 2016, 4). In the second example, Paul asks us to imagine that a group of neuroscientists invent a microchip that when implanted gives humans a new sensory ability, a sixth sense in addition to the usual five (Paul 2016, 6). Because the chip produces a sense we have never experienced before, Paul claims, "we cannot know what it would be like to experience the new, sixth, sense" (Paul 2016, 7).

Paul presents these cases as a means of motivating the following question: given the options above how could you possibly make an informed choice? She gives us reasons to suggest that making the choice based on what you think you would like as a vampire, or as an individual with a sixth sense, is morally problematic because they involve you assigning a subjective value to an experience which is epistemically inaccessible to you from your current standpoint.

Cognitive Transformative Experiences

The kinds of transformative experiences discussed by Paul are wide-ranging. However, there is one area which her account fails to address in depth: cases of

cognitive transformative experiences. A cognitive transformative experience is one which alters a person's cognitive capacities in such a way that may change the way the person thinks about their preferences, values, and beliefs. For instance, individuals who experience religious transformative experiences change not only who they are as a person, but their beliefs, values, and lifestyle. This article focuses on one particular kind of cognitive transformative experience: the experience of having dementia. Whilst this cognitive transformative experience has both epistemic and personal transformative effects, it also significantly differs to the cases Paul considers. This section will outline these differences. In spite of these differences, I argue that Paul's conclusion still holds. That is, I suggest, as Paul does, that it is morally problematic to assign a subjective value to an experience, like dementia, which is epistemically inaccessible to you from your current standpoint. This has important consequences for the issue of advance directives, which will be explored in §4. I ultimately use Paul's framework to defend the idea that preference changes which result after cognitive transformative experiences ought to be given moral weight in medical decision-making.

In order to understand the ways in which dementia differs as a transformative experience, it is necessary to begin by fleshing out what dementia is. The symptomatology of dementia is characterized by defects in several areas: memory, orientation, intellectual function and ability, judgment and affectivity (Wells 1977, 2). Early-stage dementia may result in the patient reporting problems with short-term memory and also that they are "not themselves" to their physicians (Wells 1997, 3). This alteration of character affects each individual differently and can be described as the patient experiencing an alteration of mood, creativity, enthusiasm, and a capacity to give and receive affection. Such alterations in character can be positive, negative, or neutral, depending on the individual whom is affected. As one can see from this description, early-stage dementia does not differentiate itself clearly from other disorders such as depression and anxiety, which can result in a person with dementia not receiving a diagnosis of the disorder until much later in the disease, where other symptoms tend to arise (Wells 1977, 4).

As the dementia progresses, achievement of personal ambitions and fulfillment of social responsibilities becomes less important to the individual (Wells 1977, 5). During this time, the patient becomes more likely to experience irritability and depression as their

awareness of their diminished abilities becomes apparent (Wells 1977, 6). In the moderate-stage, the dementia patient can experience trouble adjusting to change, following plans, and initiating activities.

In the late-stages of the disease, the patient often requires full-time care. Family members can describe their loved ones as being a "different" person. Some patients in this stage are depressed, lethargic, and lacking in energy; whereas others tend to be overreactive and enjoy social engagement once more. Patients in this stage experience a marked impairment in their learning ability, in their spatial awareness, and exhibit signs of motor and/or sensory dysfunction (Wells 1977, 6–7).

This description of dementia motivates one immediate difference between the kinds of transformative experiences Paul discusses and cognitive transformative diseases such as dementia: choice. In other instances of transformative experiences, the adult in question chooses to undergo the transformative experience. This is not the case for people diagnosed with dementia. One may argue that those who choose to have transformative experiences are, to a certain extent, liable for their decision and what follows from their decision. No such argument can be made with respect to patients who experience dementia.

A second, more substantial difference, is that dementia patients experience a gradual preference change, which is in contrast to the cases Paul presents. Unlike cases of becoming a vampire, dementia patients do not wake up a radically different kind of being. Instead, they have gradual preference revelations dependent on which stage of dementia they find themselves in. As Paul's transformative experience framework suggests, there is no way individuals can rationally assign a subjective value to an experience which is epistemically inaccessible to them from their current standpoint (Paul 2016, 120). The fact that dementia patients are likely to experience many preference revelations, in a short time span, gives us a good reason to think that it is simply not possible to unify a person's values in the kind of way Dworkin seems to think is possible, as outlined in §2. If one experiences a cognitive transformative experience like dementia, one's values and desires will change in ways that one will not be able to predict or control. Significantly, trying to predict and control this experience may actually harm one's future self.

A related difference is that dementia changes not only what people come to value, but also the way in which they come to value it. In so doing, it can be argued that persons who experience dementia

experience an altered sense of appreciation: both for their condition and for their prior tastes. Mrs Black appeared to experience this change. In the early stages of dementia, she expressed that she did not wish to have the disease. Motivated by this thought, she wrote her advance directive. Nevertheless, as a dementia patient in the moderate-stage of the disease, she no longer felt that way and was markedly content. Significantly, the reverse is true in certain dementia patients. A case of this nature will be explored in §4 of the article, as these situations raise particular ethical concerns which are of importance to the discussion at hand.

Similarly, dementia patients can, and often do, experience a difference in appreciation for their prior tastes. This is beautifully captured by the early-stage dementia patient Wendy Mitchell in her book, *Somebody that I used to know*:

We wouldn't get on now, you and I. Too much time has passed. We are friends who have lost touch, who now lead parallel lives. We like different things. You love the work and bustle of a busy city, whereas some days I lose hours just looking out of a window at the view (Mitchell 2018, 9).

Here Wendy explains that, from her perspective, the person she was pre-dementia feels like a different person to the person she is now, who has dementia, because they have a different appreciation for the same activities. She goes on to explore this fact elsewhere in the book, saying that she used to enjoy the taste of mushrooms but no longer gets pleasure from this experience. Instead, she gets pleasure from other activities.

Nevertheless, in order to qualify as experiencing a change in appreciation, it is necessary that one's ability to apply facts to one's values changes. For instance, we can say that I change my appreciation for meat, if knowing the facts, I decide to no longer eat it for ethical reasons. What is not clear in patients with dementia is the extent to which their appreciation for certain values change, and the extent to which this appreciation shift results as a failure to use and consider the relevant facts. As such, medical professionals often debate whether or not the preference change made by the dementia patient is truly authentic. I propose that there is an ambiguity at play here, as the dementia patient's preferences may change due to capacity or from the transformative nature of dementia itself.

An interesting analogy can be made here between dementia and cases of change preference during child-birth. Akin to writing an advance directive, women write down what pain-relief, if any, they want to

receive during child-birth. They do so whilst they have decisional capacity because they know that their preferences will likely change once the child-birth process is underway. Once the child-birth process occurs, however, these preferences can, and often do, change. One reason for this is that until you give birth to a child, you remain in an epistemically impoverished position insofar as you cannot imagine the pain of what it will be like to give birth. Whilst one could argue that the pain of child-birth puts one in a cognitively compromised situation, insofar as you may well lack the conditions necessary for decisional capacity in such a state of pain, no one holds you to your prior commitment to not receiving pain relief if you ask for it during the process.

This is where the case of child-birth and dementia come apart. Whilst the woman in child-birth can override her prior commitment to not receiving pain relief, someone in a state of severe dementia cannot override their prior commitment to not receiving pain relief. Why is this? The difference seems to lie in that we think that the dementia patient's preferences for pain relief have changed due to a change in cognitive capacity and *not* as a result of the transformative experience. This is unlike child-birth, where we think the transformative experience of giving birth is altering the prior preference.

I propose that when a patient undergoes a cognitive transformative experience, the preference change the patient experiences may be due to diminished decisional capacity, or it may in fact arise as a result of the cognitive transformative experience itself. As we have no way of knowing what has caused the new preference to arise in the dementia patient, we ought to take their newly revealed preferences seriously if we are concerned with acting in the patient's overall best interests. This fact, in conjunction with Paul's argument that we should be cautious about constraining future choices if we do not understand what having a particular transformative experience will be like, ought to reduce our confidence in the effectiveness of advance directives in cases which involve dementia patients.

One objection to my account is that persons undergo transformative experiences all the time and this by itself is not a reason to override their prior commitments. For instance, imagine you desired to have a child and now it is born, you wish you didn't have it. One may argue that you cannot override your prior moral and legal commitment by claiming that your preferences have now changed because the child has arrived.

However, both legally and morally, preference changes experienced by parents in circumstances like these are given moral weight, even if they are frowned upon in certain circumstances. This again is dissimilar to the case of dementia, where dementia patient's preference changes are not given moral weight and allowed to override the weight of their advance directive.

In fact, there are good reasons to think that the dementia patient's preferences should be given more moral weight in comparison to the parent who changes their preferences after having their child. To begin with, whilst one can claim to lack a crucial awareness of what having a child will be like, one knows what one is morally and legally committing themselves to when having a child. It isn't clear that, as advance directive writing stands, one is aware of the moral weight of advance directives in medical contexts. In addition, one's agency does not unravel in cases of personally transformative experiences. In cases of dementia in particular, one moves from a certain stage of agency at time t_1 when writing the advance directive, to a different stage of agency by t_2 , when one is severely demented. For instance, one may move from a stage of personhood, where one has full cognitive capacity and awareness, to a state of selfhood, where one only has an awareness of themselves as a being over time.⁷ I argue that the two cases, the transformative experience of dementia and the transformative experience of choosing to have a child, are not comparable for this reason.

Finally, one's appreciation of their disorder may also transform after experiencing cognitive transformation. The literature on the disability paradox gives us good reason to think that this is possible, as persons who have not experienced living with disability are less likely to rate their lives with a disability as having a high level of well-being (Albrecht and Devlieger 1999, 977–988). The concept of cognitive transformative experience offers us an explanation of why this

is: persons who are yet to have transformative experiences are not in a position to adequately imagine what their life will be like (Ubel et al. 2005). With respect to cognitive transformation, as Lily, Mrs Black's nurse pointed out, it is likely that people use this misguided assumption, that they will not enjoy their life with dementia, as motivation to write an advance directive. This is problematic given that we know that people can live a life with well-being and have dementia.

THE UPSHOT FOR THE MORAL WEIGHT OF ADVANCE DIRECTIVES

This section will examine how the transformative experience framework outlined in §3 should inform advance directive writing. I suggest that the framework generates three key principles individuals should keep in mind before writing an advance directive. I concede at the end of the section that there may be additional reasons for wanting to write an advance directive which are not covered in this article. I end this section by generating some tentative advice on what to do if, despite understanding that dementia is a cognitive transformative experience which one cannot predict or control, one still wants to bind oneself to an advance directive.

The first principle generated from the transformative experience framework is that one ought to be cautious about projecting current preferences onto a future self. One explanation of why this is comes from the general reflection principle proposed by Bas Van Fraassen. This principle runs as follows:

My current opinion about event E must lie in the range spanned by the possible opinions I may come to have about E at later time t , as far as my present opinion is concerned. (Fraassen 1995, 16–17)

If someone fails to meet the principle, then the person cannot regard herself as following a rational policy for opinion change. My account has presented reasons for thinking that before you have dementia you are not in a position to reasonably imagine the possible preferences you may come to have at the time when you are demented, due to the cognitive transformation involved. It is easy to see how the disability paradox can negatively play out in advance directive writing: one assumes that one will not enjoy having dementia and this impacts the kinds of statements one writes into their advance directive. These statements can then affect a dementia patient living contentedly with the disease, as was the case with Mrs Black mentioned in §2 of this article. The underlying

⁷David DeGrazia draws this distinction between three kinds of agency: personhood, selfhood, and subjecthood. one experiences a personhood kind of agency if one has the capacity to think, feel and deliberate, and has full mental capacity. This is the kind of agency most commonly attributed to adult humans (DeGrazia 1999, 382). The second stage of agency is 'selfhood' (DeGrazia 1999, 382). Selves are agents who, unlike persons, may not have higher-order functioning, but do have self-awareness over time. For instance, whilst young children may fall short of hitting the target of the kind of higher order functioning specified in the personhood criteria, we accept that children do have an awareness over time and, thus, can be classified as selves. The final stage of agency is 'subjecthood.' One is a subject when one has experiences and has the consciousness necessary to appreciate them (DeGrazia 1999, 382–383). For example, you could qualify as a subject if, due to a severe car crash, you had suffered severe cognitive impairments, but you were conscious and still able to feel pleasure.

motivation as to why the clinicians in Mrs Black's case were so reluctant to abide by her directive seem to be grounded in the fact that they were highly skeptical that Mrs Black even attempted to entertain the idea that she could live contentedly with dementia.

The second principle generated from the framework is that substituted judgment standards are problematic for patients who have dementia, precisely because they undergo a personal cognitive transformative experience. These kinds of judgment standards attempt to unify the values of the pre-dementia patient with the values of the dementia patient which is often not possible. This is because dementia changes what we value, and how we come to value it, gradually, over time. The concept of transformative experience gives us good reason to suspect that a person's values across one's whole life will not be in unison, as Dworkin and other philosophers assume that they are (see also McMahan 2003; Persad 2019).

One could respond that advance directives where a surrogate decision-maker is named could elude this criticism because they do not necessarily bind the dementia patient to their prior values in this way. Such measures allow for interpretation, and for the final word to go to the surrogate decision-maker. Nevertheless, this measure relies on trusting that the surrogate decision-maker will make a decision which is in the best interests of the dementia patient and not in the interests of the pre-dementia patient.⁸ Both the cases of Mrs Black and Mr White show why this assumption is problematic. Mrs Black's son desired that the advance directive be implemented because his mother, pre-dementia, did not want to be the kind of individual who could not remember her children. The transformative experience framework suggests that this motivation is irrational for wanting to write, and be legally bound to, an advance directive. Likewise, in the case of Mr White, his children fought over how to interpret the advance directive in question. Thus, the conjunction of principles one and two seems to suggest that if you are motivated to write an advance directive either to project your current preferences onto a future self or as an altruistic measure to protect

your family, both motivations are flawed. In the first instance because it is simply not possible to project your current preferences onto a future self in any kind of unified way. In the second instance because writing an advance directive which is ambiguous could lead to problems of interpretation and, in turn, more familial distress.⁹

The final principle is generated by considering the most rational course of action to take given the discussion so far about the problems of writing and interpreting advance directives. The transformative experience framework suggests that the rational action to take is to allow yourself to experience 'preference revelations' as the disease itself unfolds (Paul 2016). Such preference revelations can be positive or negative. A positive preference revelation may be an increased appreciation of social interactions in the later stages of having dementia, in contrast to not enjoying social interactions in the earlier stages of the disease. A negative preference revelation can be seen by the following case study of Mr O'Connor (Jaworska 1999). Before developing dementia, Mr O'Connor was a deeply religious man, who believed strongly in the sanctity of life. He declared that he would always want life-saving measures to be taken in the eventuality he ever got sick. Nevertheless, Mr O'Connor develops dementia, and shortly after loses his wife. He continually reports after the loss of his wife to others that he does not want to go on living. What does my account suggest is best to do in cases such as these, assuming that Mr O'Connor contracts an infection which threatens his life and has an advance directive which commits him to his prior religious beliefs? Mr O'Connor experiences a double transformative experience: a cognitive transformative experience, dementia, and a personally transformative experience, the loss of a loved one. My account suggests that his change of preference in his valuing of his life could arise from his neurodegeneration, or that it could arise as a result of having both of these transformative experiences. As we cannot know either way, my account suggests that we take Mr O'Connor's preferences seriously. That is, if Mr O'Connor does get sick, has an advance directive which commits him to his prior religious beliefs, and is still maintaining he does not wish to be alive, it follows from my view that we ought to listen to Mr O'Connor's beliefs as a dementia patient and disregard his religious

⁸This strategy is also problematic given what the literature on leeway in advance directives informs us. Subjects vary greatly as to how much 'leeway' they would give to their surrogate decision maker to override their advance directive. A study on advance directives and dialysis patients illustrates this: 39% of the patients desired to grant 'no leeway' to their surrogate, 19% a 'little leeway', 11% a 'lot of leeway', and 31% 'complete leeway' (Sehgal et al 1992). A patient from a different study in the leeway literature nicely captures the concern: "if you have a lot of confidence in the other person to have your best interests at heart, it would be O.K., but that may not always be the case, even with a relative" (Fried et al. 2013).

⁹It is worth noting here that advance directive writing does not necessarily have to be ambiguous. I am merely suggesting that the kinds of advance directives which are currently written tend to be ambiguous and thus often lead to interpretative problems of the nature outlined here.

preference pre-dementia. According to my view, dementia patients can have positive or negative preference revelations, and both ought to be given moral weight by clinicians. Moreover, it seems that clinical practice has already moved in this way; my account is just shedding light onto why this may be.

I admit the possibility that there may be motivations which I have not adequately addressed in this article which remain legitimate reasons why an individual may desire to bind themselves to an advance directive. What measures can one take if, understanding the transformative nature of dementia, one still seeks to write an advance directive and bind oneself to it?

The following suggestions are tentative and have policy implications which cannot be fleshed out in sufficient detail in this article. Nevertheless, it is clear that my account favors stricter regulations on advance directive writing because the way that advance directives are currently written, and interpreted, is not helpful to clinicians who have to balance the considerations stipulated in an advance directive with the well-being of the patient they see before them. Therefore, I suggest that if one wants their advance directive to be implemented in clinical practice, one ought to be cautious both with respect to how one writes an advance directive and how one thinks their directive could be interpreted. With respect to writing, it is inadvisable for individuals to use websites which promote 'easy' advance directive writing, as the transformative experience framework has shown us, at the very least, that advance directive writing is not easy (Advance Directive for Dementia 2020). My account gives us good reason to think that such websites should be banned. Consequently, it seems advisable for individuals in this position to seek guidance from both lawyers and clinicians, in order to increase the possibility that their directive be taken seriously in a clinical setting.

However, as the case of Mr White illustrates, taking these steps with writing is not sufficient to ensure that one's directive will be implemented. In order for this to be the case, one needs to ensure that the interpretation of one's advance directive is relatively straightforward for medical professionals and loved ones. There is no easy means of achieving this end, but early discussions with medical professionals and loved ones could help. For instance, both parties need to know *how* binding you desire the advance directive to be, and, more importantly, *why* you want it to be binding. In Mr White's case, it was not clear that, given the stage of his illness at the time the advance

directive was drawn up, and the fact that he was only motivated to write it because his children desired him to, he could adequately answer either question. Likewise, it isn't clear from Mrs Black's case how legally binding she desired her advance directive to be. Ambiguities such as these making interpretation difficult, if not impossible, for medical professionals.¹⁰

CONCLUSION

This article has proposed reasons why one may want to have reduced confidence in writing advance directives. I began by presenting the received view put forward by Ronald Dworkin, which argues that advance directives ought to have significant moral weight when considering how to act in a dementia patient's best interests. I suggested that his account fails to consider an important variable which ought to hold moral weight when considering how to act in a patient's best interests. This variable is cognitive transformation. This article presents reasons why experiencing cognitive transformation can affect a person's beliefs, values, and preferences and why it is important to take these new preferences seriously. I suggest that this account can help to explain why it is that clinicians are reluctant to give moral weight to advance directives in medical decision-making. In so doing, my account aligns philosophical theory with current clinical practice.

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¹⁰One tentative policy implication, then, is for clinicians and lawyers to actively discourage patients from using ambiguous phrases in the wording of their advance directives. In addition, it could be required that persons who write an advance directive answer both of these aforementioned questions in as much detail as possible.

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