

# Socially and temporally extended end-of-life decision-making process for dementia patients

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## ABSTRACT

There are two contrasting views on the decision-making for life-sustaining treatment in advanced stages of dementia when the patient is deemed incompetent. One is to respect the patient's precedent autonomy by adhering to advance directives or using the substituted judgement standard. The other is to use the best-interests standard, particularly if the current judgement on what is best for the incapacitated patient contradicts the instructions from the patient's precedent autonomy. In this paper, I argue that the protracted clinical course of dementia over many years requires the extended perspective of a progressive decision-making process—extended in both social space and time. The ongoing debate between these two competing views has missed this perspective by focussing on an exclusive disjunction between the competent former self and the incompetent current self. Drawing on theories of situated cognition in cognitive science, I will show that the cognition of a demented patient can be viewed as extended and embodied by her supportive social environment. As the disease progresses, the content of the mind of a demented person becomes partially constituted by such external resources along with her diminishing intrinsic mind. With this understanding, medical decision-making for a demented patient can be construed as a temporally and socially extended practice. A collective decision-making body consisting of the patient, her family and surrogates, and the clinician, should make progressive decisions as a whole over years of the disease course. Finally, I will provide a practical example of how this proposal can be applied in clinical practice.

The moral justification of the past-competent self-dictating medical decisions of the presently demented self in the form of advance directives and the substituted judgement standard has been a subject of unsettled debate over the past few decades.<sup>1–11</sup> The fundamental challenge is found in the fact that advance directives and substituted judgement can be in direct conflict with the best-interests judgement of a presently incompetent dementia patient who seems to be content with the disability without any obvious suffering. In what follows, I will critique two prevailing views and provide an alternative conception of decision-making. My discussion pertains only to degenerative dementia (such as Alzheimer's) and end-of-life decisions (such as intubation, artificial nutrition and antibiotics).

## TWO COMPETING VIEWS

The mental incapacity of degenerative dementia sets in very slowly and gradually over the course of many years, during which not only cognitive capacity but also the personality, interests and preferences of the

patient slowly but radically change. This clinical feature presents unique moral challenges that are not seen in cases of other cognitive disabilities that have relatively sudden onset and stable course thereafter, such as anoxic brain damage, stroke and brain injury. Generally, autonomy-driven end-of-life care planning presupposes that the values and preferences of patients remain stable over the course of the plan. But in the case of dementia, there is a sense that the person and the self change slowly and radically over many years. The competent former self who issued an advance directive years earlier may be drastically different from the incompetent contemporary self who is the subject of a critical medical decision now.

The case in point is a repeatedly cited case study of Margo, which Ronald Dworkin developed based on an essay by a medical student about a patient with Alzheimer's disease.<sup>2–5</sup> An abridged version of the hypothetical scenario is as follows:

Margo is a 55-year-old patient with Alzheimer's disease. While her memory deficit and spatial disorientation were severe, she was apparently enjoying her life, reading the same mystery book randomly, listening to the same music, and painting the same logo repeatedly. There was no sign of distress, and in fact the medical student who regularly visited her remarked, 'Margo is undeniably one of the happiest people I have known.'<sup>12</sup> But Margo had executed a living will when she was first diagnosed with Alzheimer's, directing that no treatment be given to her if she contracted a serious life-threatening illness. Now Margo contracts a life-threatening infection which is still easily treatable with antibiotic treatment. Should her living will be honoured and the antibiotics withheld? Or does her present contentment make her continued life worthwhile and override her past directive?

Dworkin argues that advance directives allow people to ensure that their final years are guided by the critical interests that shaped their earlier lives. Even if Margo is content with her current life with simple pleasures, and even if she pleads for life-prolonging treatment, he argues, her surrogate should abide by her previous directive, because she has no capacity to exercise her contemporaneous autonomy. He writes:

Our argument for the integrity view, then, supports a genuine doctrine of precedent autonomy. A competent person's right to autonomy requires that his past decisions about how he is to be treated if he becomes demented be respected *even if they contradict the desires he has at that later point.*<sup>2</sup> (p. 228, emphasis added)

This argument holds that a patient's critical interests, or the values and preferences that

characterise her life, cannot, and should not be trumped by what is perceived by others as her best interests. An advance directive to forego life-saving treatment, if and when the patient becomes demented, is an autonomous expression of such a critical interest. Moreover, we are all allowed to sacrifice our experiential interests of the here-and-now for the sake of greater critical interests that extend throughout our lives. Therefore a demented patient should also be allowed to sustain her autonomous decision expressed while she was competent, even if it is against her contemporaneous experiential interests. I will call this argument the Pure Autonomy Argument (PAA), which presupposes a self that is steadfastly committed to a stable set of character-defining values and life plans, a self that maintains continuity over time despite dementia.

In contrast, the opponents subscribing to the primacy of the best-interests standard argue that such a past directive is 'the tyranny of the timeless moment of choice' (p. 85 in The President's Council on Bioethics<sup>11</sup>) because we deny people like Margo the freedom we enjoy as competent people to change our decisions that conflict with our subsequent experiential interests. (p. 35 in Dresser<sup>5</sup>) They further argue that we all have insurmountable difficulties in predicting our own wishes and preferences in the future, particularly when we go through drastic cognitive and personality changes. Therapeutic options and prognosis can change between the time the advance directive is issued and the time it is implemented. It is unjustifiable for the former competent self to control the end-of-life decisions of the later incompetent self through such highly speculative directives.<sup>3</sup> As Berghmans asserts, "at the time you would most likely 'change your mind', you don't have enough mind left to change."<sup>10</sup> Moreover, there are many empirical studies demonstrating the limitations of advance directives and the unwillingness of the general public to implement them.<sup>13</sup> Instead of following past, outdated and uninformed instructions, they argue, 'no legal instrument can substitute for wise and loving choices, made on the spot, when the precise treatment dilemma is clear and care decisions are needed' (p. 56 in The President's Council on Bioethics<sup>11</sup>). I will call this argument the Pure Beneficence Argument (PBA), whose fundamental premise is that the current demented self has lost critical connectivity with the former competent self. It lacks sufficient competence to exercise renewed autonomy for the wholly different situation that it has never experienced before.

PAA and PBA are undoubtedly at two ends of the spectrum. Several recent commentators have presented various reconciliatory views to find middle ground.<sup>14–16</sup> In what follows, I will present an alternative conception of decision-making that will integrate PAA and PBA into a pragmatic solution.

### ERRONEOUS DISJUNCTION

The fundamental problem that is common to these competing arguments is, in my view, their exclusive disjunction of our focus between the autonomy of the competent former self versus the best interests of the incompetent current self. The reason behind such disjunctive theories lies in the prevailing notion that decision-making competence is a threshold concept. When dementia progresses slowly, the patient crosses this threshold at some point in time, after which he is deemed completely incompetent. In reality, the patient undergoes many years of very slow and gradual decline of cognitive function, during which many things internally and externally also undergo slow transformation with considerable fluctuations on occasion. The debate between PAA and PBA focuses on two separate points in time: a time before the threshold and a later time after the

threshold, not attending to the intervening period, which usually extends from several years up to a decade or more. Not only are these disjunctive views incongruent with the clinical reality of dementia patients, but they lose sight of the window of opportunity to provide pragmatic guidance.

This consideration poses challenging questions to both PAA and PBA. First, the question of PAA: How far into the disease progression does PAA consider the patient sufficiently autonomous to amend her directive? Suppose two years into her disease that Margo decides to rescind her previous directive, realising that she now feels happier and wants to receive life-saving antibiotics and artificial nutrition as needed in the near future. Is this considered a renewed expression of autonomy, albeit less than optimal? One answer might be that, once the disease starts and cognitive functions slowly decline, any decision might be less autonomous than the ones made prior to the onset of dementia. Thus, a PAA advocate may say that we should only admit the directive that she made prior to the onset. But this answer begs the question: Why is the patient not allowed to amend her directive merely because she was diagnosed with dementia two years ago? An alternative answer would be to allow an amendment just until she crosses the threshold of competence, since the more recent the directive the better. But why is the patient not allowed to amend her directive the day after she is deemed to be incompetent, provided that her cognitive function does not change significantly over one day? Similar challenges are also posed to PBA proponents: When does the former competent self end and the current incompetent self start? Suppose an amendment to her directive is made one week before crossing the threshold of competence. Do PBA proponents respect this amendment one week after the threshold is crossed, even if it turns out not to be in her best interest? Of course, the threshold is a somewhat arbitrary landmark in the disease progression; unless a clinician has a reason to formerly assess competency, the threshold is unknown. Thus the question is mostly hypothetical, but the point is all the same: How far is a demented patient allowed to change her mind and how much should the clinicians and family respect such an amendment if it contradicts her advance directive (question to PAA) or her best interests (question to PBA)?

However, there are at least two important reasons why PAA and PBA both focus on only these two stages of the disease progression, being fully competent or fully incompetent. First, clinical reality seems to impose this dichotomy because living wills are often issued when the patient is competent, and then it is never reviewed or updated until the patient becomes incompetent. This long interval is the problematic reality that PAA and PBA deal with. If so, we should address this reality directly instead of upholding the dichotomy it has imposed. Second, the juxtaposition of the two selves of one person at these two points in time reveals the underlying metaphysical and moral questions most perspicuously, including the persistence of personal identity over time, and the value, the character and the dignity of a person's life as a whole. As important as such a contrast may be for theoretical discourse, however, these two 'pure' arguments seem to have lost their ability to provide practical guidance during the intervening years that could stretch up to a decade.

### AN ALTERNATIVE CONCEPTION OF DECISION-MAKING

The fundamental flaw of PAA and PBA, then, is to consider the end-of-life decision-making of dementia patients as a punctuated *event*: an event to execute an advance directive when the person is fully competent but has no first-hand knowledge of what it is like to be demented, or an event to implement needed

care when the patient is fully incompetent and unable to provide any input. But the decision-making need not be such two separate events at either end of the spectrum. Rather, it should be an ongoing *process*. Medical decision-making in general, and end-of-life decision-making in particular, is fundamentally a social practice that encompasses the social dimension and historical timeline of the patient's life as a whole. This process should be constituted by the patient's community, and stretched out through the progression of her disease from diagnosis through death.

In order to conceptualise this decision-making as a socially and temporally extended process, I will borrow an unconventional concept of situated cognition that has been a subject of ongoing discussion in the philosophy of mind and cognitive science.<sup>17–19</sup> In a nutshell, the theories of situated cognition propose to view and conceptualise our mental processes and mental states as embodied, embedded and extended in the environment beyond the brain. According to the traditional view, human cognition is an abstract, standalone, computer-like information processing system that is housed in the brain and interfaces with the world through inputs (perception and sensation) and outputs (language and action). Against this backdrop, the theories of situated cognition view human cognition as an extended system beyond the brain and the skull, involving, and sometimes constituted by, not only the brain, but also the body and the natural and social environment.

The implication of this non-traditional understanding in cognitive science in dementia care is potentially enormous. The cognition of demented patients, according to traditional views, just fades away inside the failing brain. In contrast, the theories of situated cognition raise a possibility that we can locate their cognition outside their failing brains. Take an example of the extended mind thesis, one type of the theories of situated cognition. Clark and Chalmers present a case study of a demented person in a thought experiment.<sup>19</sup>

Otto suffers from Alzheimer's disease, and ... he relies on information in the environment to help structure his life. Otto carries a notebook around with him everywhere he goes. When he learns new information, he writes it down. ... For Otto, his notebook plays the role usually played by a biological memory. Today, Otto hears about the exhibition at the Museum of Modern Art, and decides to go see it. He consults the notebook, which says that the museum is on 53rd Street, so he walks to 53rd Street and goes into the museum. ... the notebook plays for Otto the same role that memory plays for [a non-demented person]. The information in the notebook functions just like the information constituting an ordinary non-occurrent belief; it just happens that this information lies beyond the skin. (pp. 12–3)

We all rely on external resources to enhance our cognitive function, but demented persons need to do more. Otto's mind extension need not be limited to a notebook. Socially extended cognition is very important in the decision-making process of dementia patients.

What about socially extended cognition? Could my mental states be partly constituted by the states of other thinkers? We see no reason why not, in principle. In an unusually interdependent couple, it is entirely possible that one partner's beliefs will play the same sort of role for the other as the notebook plays for Otto. What is central is a high degree of trust, reliance and accessibility. In other social relationships these criteria may not be so clearly fulfilled, but they might nevertheless be fulfilled in specific domains. For example, the waiter at my favourite restaurant might act as a repository of my beliefs about my favourite meals. ... In other

cases, one's beliefs might be embodied in one's secretary, one's accountant, or one's collaborator. (pp.17–8)

## EXTERNALISM OF DECISION-MAKING

If I follow this conception of socially extended cognition, a dementia patient's beliefs might be partly embodied in her family, surrogate or whomever she trusts. Then, she is viewed as a socially and temporally situated and extended being in her environment. As her cognition slowly declines in the brain, her external and extended system of cognition can increasingly support and embody her mind, and perhaps partially constitute her cognition. With this view, the end-of-life decision-making process becomes a type of social practice—a concerted effort of several participants who play unique social roles. As their roles slowly and gradually transform with the progression of the disease, the role of the patient becomes progressively limited, and the role of the supportive personnel expands. The role of clinicians is to provide necessary medical information at each turn of events, and supervise this slow transition and see to it that the system works as expected.

The planning and decision-making of dementia care, then, becomes an extended process—extended in the sense of time and social space—as opposed to an isolated event that happens before or after the mental devastation. Instead of an exclusive focus on advance directives or contemporaneous well-being, the decision becomes an output of an ongoing and longitudinal team project, which considers not just an interpretation of prior directives and the assessment of the current status of well-being, but the social and historical context of the patient's life as a whole. The decision always applies to her condition contemporaneously, yet covers all the relevant factors the patient herself cannot deliberate on her own.

The fundamental difference of this extended system of decision-making from PAA is that, while advance directives and precedent autonomy are important factors, the patient and the team have the flexibility to amend or even rescind them according to what develops in and around the patient, including her medical condition, what has developed in her community since her original directive was issued, and her own inclination. Obviously, this system is also different from PBA in that the best-interests judgement can be trumped by other considerations; the team might still decide on a treatment plan that is against what is considered 'objective' interests. But the most important merit of the extended system of decision-making is its longitudinal continuity. The team can follow the progress over the course of several years to a decade, during which it can trace the consistency and integrity of care. This point is critical because it is only with this continuity of assessment that the inference of substituted judgement about the patient's precedent autonomous wishes and preferences is most relevantly balanced against the current best-interests judgement.

As a footnote, somewhat similar conceptions of the person and the self that are situated and embodied in the social and historical environment are seen in existentialist (eg, Heidegger) and communitarian (eg, Charles Taylor) philosophers. Drawing on them, Hughes adopted a 'situated-embedded-agent view' of a demented person and came up with a similar conclusion.<sup>20</sup> More recently, Nelson applied the extended mind thesis or 'active externalism' to the advance directives of dementia patients, and proposed to view such directives as "parts of our minds, parts of ourselves, ... more akin to our (dispositional) memories, ... 'uncanceled' acts of moral agency".<sup>21</sup> Unlike my proposal he seems to uphold the primary authority of such

directives as ‘Ulysses contracts’, which, by virtue of being an extended system, is considered a contemporaneous state of the agent. Two notable differences of the present proposal from these previous ones are: first I extend the agency into the patient’s supportive human environment and consider this extended system, as a whole, a collective decision-maker. Second, I propose based on these theoretical backgrounds an implementable pragmatic approach to which I will turn next.

### PRAGMATIC APPROACH TO DECISION-MAKING

A lesson we learn from the innovative theories in cognitive science is that we can understand the cognition of a demented patient as an interplay between her failing brain and her supportive environment. The relationship between the demented patient, her caregivers and the healthcare professionals can be construed as an extended system of one collective decision-maker. To succeed in this endeavour, the group needs to meet and review the assessment and plan periodically. The best time would be whenever there is any significant development in the patient’s medical condition or her life, such as a hospital admission, a loss of family members, a move into the nursing home, etc. These are the times when the patient and the family can focus on the preferences for life-sustaining treatment. The best place would be at the clinician’s office, hospital room, or wherever the clinician can coordinate the meeting. Note that, unlike regular living wills, the process necessarily involves clinicians, who should play the lead role as a coordinator of this process. The clinician should provide necessary medical information, review any interim progress since the last meeting, lead the discussion and document the decision. The clinician can also monitor and ensure that the surrogate exercise appropriate fiduciary duties.

There are several advantages of this approach over traditional care plans, particularly those based on PAA and PBA. First, since the process is initiated and monitored by clinicians, it ensures the documentation of updated, specific information coming directly from the patient and the surrogate, obviating the problems that plague conventional living wills, which are often outdated, uninformed, unspecific and misplaced. The decision is about events that might happen in the near future, and since the patient is already in the disease process, she may have first-hand insight into her own well-being. The patient and the surrogate can come up with a more practical decision than previously issued speculative directives. Second, the voice of the patient herself is reflected in the decision to an extent appropriate for her disease progression. This contemporaneous preference is carefully balanced by the surrogate and the clinician against her previous preferences and contemporaneous interests, considering her personality changes and her current degree of cognitive deficit. Again, the insight of the clinician is indispensable in this assessment.

But this proposal may appear too idealistic to be implemented in real situations. What if the patient has no family or relatives? Are clinicians generally not suited to coordinate such meetings and too busy to take care of such issues? Is there a danger of paternalism? To address some of these concerns, I will first point to a practical example that is very close to this proposal and has been successful. The Physician Orders for Life-Sustaining Treatment (POLST) program has been developed and used in the State of Oregon, USA, since 1995 and is now used in several other states in the USA.<sup>22 23</sup> This voluntary programme embodies at least part of this proposal. It uses a concise form containing specific medical instructions that can be acted on immediately by nurses, doctors and emergency personnel. The

key differences from living wills are the following. (1) Instead of being signed by a patient privately, the POLST is a medical order that is completed and signed by a clinician after consulting with the patient and/or her surrogate. Since it is a medical order, the wishes and preferences of the patient and family are clearly translated into specific end-of-life orders (resuscitation, intensive care treatment, antibiotics, and artificial nutrition and hydration) that can be acted upon by any professional. (2) It stays with the patient and is readily available to any healthcare provider who attends to the patient (it is now also available electronically in Oregon). (3) It is completed most typically when the patient develops life-limiting conditions, not when the patient is generally healthy and has no idea of serious illnesses. It can be updated whenever the patient’s condition significantly changes according to the judgement of the clinicians.

While the POLST is not specifically intended for dementia care, by initiating this process at the time of diagnosis and following up periodically, the care team can transcend the exclusive disjunction that PAA and PBA poses and reach a pragmatic solution. Of course, the POLST does not completely replace living wills, but by virtue of its ease of completion and deployment in real clinical settings, and clinician’s supervision, it should be a valuable model for the extended and progressive decision-making of dementia patients. In some parts of the world, such longitudinal care planning, led by specialised geriatricians, primary care physicians and other providers, has already been implemented. For such practices, this proposal should give a theoretical underpinning for a collective decision-maker that includes the team, the surrogate and above all the incapacitated patient herself.

Some might still argue that the role of the clinician in this proposal is problematically paternalistic, because she initiates this process on her own initiative, and she may override an advance directive. Paternalism is considered bad precisely because it overrides the autonomy of the patient who is making a decision. When the patient lacks the capacity to autonomously initiate the necessary process of his medical care, providing the *means* to enable the patient to keep track of the necessary medical care, as opposed to providing the *decision* itself, should not be considered paternalism. If this is still viewed as paternalism, it might be considered as ‘soft’ paternalism, which can be acceptable in certain situations. Regarding the override of the advance directive, it is an erroneous premise, in my opinion, that an advance directive is a permanent, immutable truth of the patient’s wishes and preferences over the entire course of the protracted illness. When the patient has lost the ability to autonomously amend, update, interpret, qualify and specify the directive, updating the care plan according to the renewed clinical reality in a form of a medical order is not paternalism. It is uncontroversial for a clinician to write and sign a medical order after discussing available courses of action and alternatives with the patient and family, even when it may override a living will that is unspecific about the problem at hand and is outdated. The present proposal is not to replace the previously expressed preferences with the physician’s recommendation, but to update and specify the preference of the extended decision-maker to respond to the renewed clinical question here and now.

Another objection that might be raised is that, even though external cognition may remember and evaluate, it is impossible for a socially extended decision-maker to be autonomous. My response to this objection is that we should start from the stark reality—the empirically well-established premise—that a genuinely and truly autonomous decision by a patient with advanced dementia is impossible and unavailable. Once this premise is

established, the question is not whether this proposal approximates a counterfactual and fictitious ('if he were as competent as ten years ago, then ...') autonomy of the presently incapacitated patient, or a past autonomy of a past person in the advance directive, as PAA insists, but which alternative arrangement—an alternative that does not presuppose an imaginary autonomy—is more practical and morally acceptable. I have argued that what emerges when the intrinsic self gradually becomes devastated and fades away as the disease progresses into advanced stages of dementia is the socially and temporally extended self, which can function best as a practical decision-maker.

## CONCLUSION

Drawing on the concepts of the extended mind thesis, I have presented a view that a collective decision-making body constituted by the failing mind of a dementia patient and the supportive human environment can jointly extend the decision-making process in social space and time with sufficient continuity, which can transcend the intractable dichotomy between PAA and PBA. I submit this as the starting point for a more pragmatic and implementable theory of surrogate decision-making for dementia patients.

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