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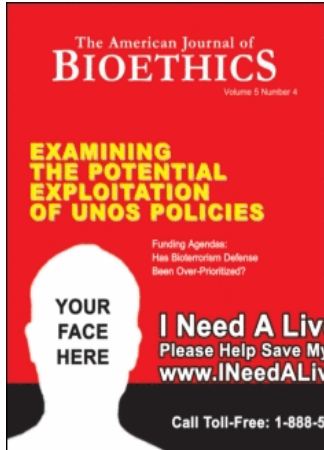
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# **Beyond a Dworkinean View on Autonomy and Advance Directives in Dementia. Response to Open Peer Commentaries on “Would We Rather Lose Our Life Than Lose Our Self? Lessons From the Dutch Debate on Euthanasia for Patients With Dementia”**

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*But it must be said from the outset that a disease is never a mere loss or excess—that there is always a reaction, on the part of the affected organism or individual, to restore, to replace, to compensate for and to preserve its identity, however strange the means may be: and to study or influence these means, no less than the primary insult to the nervous system, is an essential part of our role as physicians. (Sacks 1986, 4)*

Caregivers working in long term care facilities are regularly confronted with (mostly) gentle disagreements among residents and their relatives with regard to the goals of care and the appreciation of living a life in dependency. The latter are often puzzled by the fact that the former express themselves positively on their quality of life, notwithstanding the fact that their actual existence strongly contrasts with formerly held standards: their affirmation of life seems almost ‘out of character’. This adaptive phenomenon is so typical and widespread that researchers invented a term for it: the disability paradox (Albrecht and De Vlieger 1999). When it occurs, this phenomenon is perhaps most striking in individuals who once held very outspoken negative beliefs regarding a life with chronic illness and who even—as de Beaufort has done—completed an advance directive to the effect of preventing this seeming paradox to occur. “(B)ecause what (they) want to prevent is precisely

this fact that (they) will experience things differently” when the condition feared for eventually arrives (de Beaufort 2007, 57). According to Davis, these ‘autonomy freaks’ (perhaps ‘control freaks’ is even a better term) must not only mistrust their doctor for not complying with their advance directive, but they also have to mistrust themselves because there is a good chance that in the end they will not act in accordance with their earlier values (Davis 2007, 60).

Of course, as long as one’s decisional capacity is unaffected, advance directives don’t take effect; authors have ample opportunity to live up to challenging experiences and adapt to new situations and conditions, disabilities included. Perhaps, in looking back afterwards, they will draw the conclusion that, at the time they filled out their advance directive, they truly underestimated their ability to accommodate to new circumstances in life. Indeed, Goering’s comment touches the core of the matter where she states, “our anticipatory beliefs often fail to recognize our ability to adapt” (Goering 2007, 62). In our opinion, the existence of a disability paradox can be seen as a strong empirical argument against Dworkin’s distinction between experiential and critical interests, and against his view on human life as an autonomously shaped narrative unity (Dworkin 1994).

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The fact is that most people with Alzheimer's disease (AD) act and respond in very much the same way as those who are confronted with a very serious physical disease. A growing number of studies on the patient's perspective demonstrate that people with AD are actively involved in interpretative efforts to make sense of their fractured world (Hertogh et al. 2007). They too try to adapt to the changes that are occurring and are struggling to hold on to a sense of self and identity (Sacks 1986). In addition, there is also evolving empirical evidence that people with early stage AD who also have an advance euthanasia directive (AED) tend to push back their frontiers and postpone the execution of their AED to an undefined future (Hertogh and de Boer 2006). Also, in this respect they do not differ from sufferers from purely physical chronic illnesses. So, while it goes without saying that care givers will offer all the possible help and support to the non-demented chronically ill elderly in answering the adaptive challenges they face, what valid reason can there be for not responding to the actual and quite similar needs of people with dementia? Don't they have a right to their own disability paradox?

In day-to-day reality such questions seldom rise in this form, as caregiver and patient are always already engaged in a responsive care-giving process, a process that often starts long before a clear diagnosis has been established and that follows (and accommodates to) the gradual and fluctuating progression of the disease. In this process there is adaptation and change from both sides.

The problem we have with the comments of de Beaufort (2007), Woien (2007) and Davis (2007) is that all three of them, more or less in the wake of Dworkin's concept on human life, reflect a rather abstract view on persons and (the phenomenology of) dementia. They emphasize states and dichotomies while underplaying adaptive processes and continuities. They contrast present and previous persons, current and precedent views, informed and trivial preferences, but pass over the ominous absence of a clear-cut border between a (severely) demented and a non-demented state of living. Davis' thought experiment and comparison of dementia with an 'alien invasion' even evokes associations with ancient ontological conceptions of disease, as if there would be an abrupt transition from a state of health to a severely demented condition.

All of these views are far from the lived reality and the complexity of care-giving practice. Dementia, specifically Alzheimer's Disease, is not a 'state' allowing a clearly circumscribed pre- and post-demented point of view. It is more appropriately defined as a process of "insidious onset and progression," as many medical textbooks state. Although this phrase typically represents the view of an external clinical observer—and neglects the subjective experience of the patient referred to above—the word 'insidious' does reflect something of how the process is experienced by those involved. We agree with Woien (2007) that we don't provide a "strong theoretical reason" for not complying with an AED of a patient with advanced dementia, but then we disagree with her framing of the moral problem as being mainly

one of conflicting preferences. Instead, our intention was to describe the multiplicity of reasons underlying the moral dilemma's created by AEDs of patients with advanced dementia, informed by clinical experience and the practice of care giving in dementia. The issue of conflicting preferences is only one of them, and we must add that this conflict arises within a long-standing relation in which family members continue to recognize the person with dementia as their dear one. We referred to the heavy burden AEDs impose on doctors and proxies in that such a document makes them responsible for deciding on the right moment for ending the life of the person with dementia. We called attention to the moral problem of disregarding the voice and needs of the current patient and we discussed the difficulties related to the assessment of (current) suffering. We do believe that Goering (2007) has a point in contending that, as a consequence of our appeal to take the patient's perspective seriously, we must also be sensitive to signs of unbearable and hopeless suffering. However, it is of great importance not to confuse suffering due to inferior palliative care with this criterion for lawful euthanasia. We are not only doubtful about the ability of someone with advanced AD to value his situation in these terms, but we also know from experience that an intersubjective agreement on the desirable course of action (euthanasia) can no longer be reached in this stage of the disease. Indeed, the impossibility of dialogue and intersubjectivity between doctor and patient, not only in the process of decision-making but also in the actual performance of the life-terminating act, is perhaps the gravest obstacle to complying with an AED of a patient with advanced Alzheimer's. In this situation, to "honor" the AED (as Woien [2007] considers to be the right solution to the moral conflict from her theoretical standpoint) is a misleading euphemism for killing a person with dementia. Imagine how this should be done in case of an incompetent but still alert and conscious patient with advanced dementia, to whom we cannot explain that in a forgotten past this was what he wanted to happen to the demented person he has now become?

In view of this absurd scenario, we made a plea for an ethical debate on the limits of anticipatory choices or, more precisely, on what can be asked from others—doctors and relatives—when it comes to providing oneself a 'self'-controlled death in case of dementia. Apart from the very rare instances of assisted suicide we described—cases that in turn raise several serious questions regarding diagnostic scrutiny, compliance with legal requirements, and representativeness—the chances to realise this ultimate type of help and assistance are very feeble. In the Netherlands, there is a discussion on making a suicide pill available, specifically for elderly people who are weary of life and/or fear the perspective of progressive dementia. This would indeed relieve the responsibility of doctors and relatives to some extent, but the provision of such a pharmaceutical instrument of control (apart from the whole range of ethical and practical concerns it raises) offers no guarantee that people will actually use it at the originally meant occasion. Having a suicide pill at one's disposal may give people

a feeling of control, but this will not prevent them from getting engaged in an adaptive process in case the feared condition arises, leading them to revoke formerly held beliefs. The option of pre-emptive suicide, as suggested by Davis (2007), seems hampered and bound to fail for similar reasons, which leaves us with Battin's (2007) timed-release euthanaticum implant. Indeed, her thought experiment offers a stimulus to reflect on novel options with regard to the challenge of an old age with AD. However, Battin's 'third alternative' is still an alternative within the paradigm of autonomy as this concept is generally conceived of in the standard literature of bioethics. It points primarily towards a further technical enforcement of our possibilities for control and independence. But maybe the deepest lesson to be learned from the 'dementia debate,' as we described it (Hertogh et al. 2007), is that it illustrates the shortcomings of an ethic too unilaterally oriented towards these values. In a way, the tragedy of Alzheimer's is the tragedy of this attitude to life. In our opinion, a real alternative is only to be found in an ethic that is open to the (inter)dependency and intrinsic vulnerability of human life as they are revealed by the fragile existence of people with disabilities and chronic illness, including dementia. Apart from the ones already mentioned in our paper, this is an additional reason for including the patient's perspective in developing research with regard to treatment and care-giving, including end-of-life care in dementia. This kind of empirical research will help us to move beyond the abstract Dworkinian view on autonomy and the deadlocks it results in. ■

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