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Dementia, transformation, and advance directives

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Our core claim is that the loss of competence One patient, Dr X, is a retired physician. His dementia caused The increasing age of the population and him to be lost in familiar areas, unable to make sense of what does not entail the absence of valuing, caring, or increasingly early detection of conditions that cause he was doing or where he was going. He planned for suicide-dementia such as Alzheimer's disease in their exercise of the will that commands respect in an attitude toward which he has mixed feelings now, saying prodromal stage mean that writing advance treatment decisions Interviews with patients who that his wish "seems very strange now, looking back" but also had been cured of dementia in the via successful directives prior to becoming demented is becoming saying that he would not want to live if his cognitive dementia more common. In this paper we examine the moral treatment for normal pressure hydrocephalus returned, as this would prevent him from engaging in the authority of advanced directives. Advance directives reveal that patients retrospectively endorse the activities he loves. (He adds that people of the right temperament and with good support could live happily with made by patient can decline medical care for their continuity of their values throughout their period dementia.) future incompetent self. When a demented patient of dementia. In addition, the quality of these The second patient, S, is a retired engineer who describes his values at the time of dementia seem to be of the lacking capacity expresses a desire to make a experience of dementia this way: healthcare decision that is contrary to that prior appropriate sort to demand respect from the "One of the scariest things is - in conversation the sudden... advance directive, the status quo is that the standpoint of autonomy. impact [of realizing] I used to know what those words meant, advanced directive takes precedence. We examine and now I don't. I knew that I had known how to do other the authority of advance directives in an important things, and the ability had escaped me...I was working in my yard, and I was in a flowerbed that was elevated several feet class of dementia cases: those in which patients' above the ground, and I had the instant realization that I don't current best interests appear to conflict with their know how to get down. Driving one day – where am I? how past instructions.

Problem Statement

Are there situations in which a demented patient may overrule their advance directive?

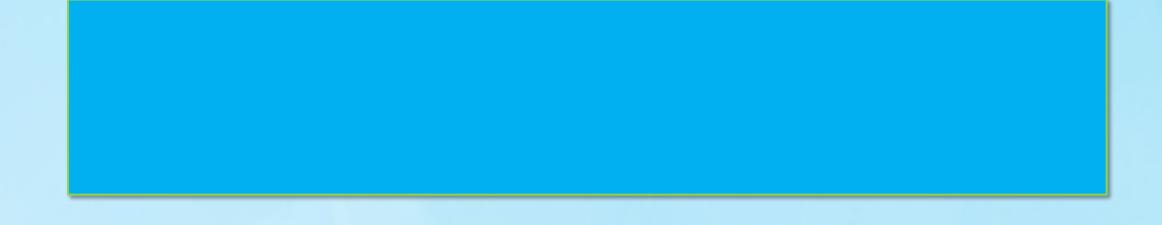
- did I get here? How do I get back?"
- Remarkably, after a series of misdiagnoses that S refused to accept, he managed to find the correct diagnosis himself through studying medical journals. S now says that he would not want an advance directive, were he to become demented again, but would instead prefer to make his own treatment decisions.
- With all appropriate caveats about limited data, what should we make of these cases? Two points are salient. First, both Dr X and S retrospectively described the *continuity* of their values before and during dementia: Dr X valued independence, and time with his horses and dogs; S retained

- Nine patients who had dementia secondary to Normal Pressure Hydrocephalus were identified and interviewed to generate a qualitative ethnography.
- These patients had documented dementia, and had recovered completely or near-completely after successful placement of a ventriculoperitoneal shunt.
- Interviews and review of philosophical and scientific literature on dementia were synthesized into philosophical arguments.

his commitment to his social relationships. Dr X explicitly describes himself as having retained his values. S kept his commitment to social connections and now, as a result of his experience, volunteers at a hospital and works with patients who may have NPH. Thus it's fair to say their values were not altered by the experience of dementia.

• Second, their attitudes *at the time of dementia* seem to be of the appropriate sort to demand respect from the standpoint of autonomy. Here we want to be agnostic about the precise nature of attitudes that command this respect, while suggesting that the attitudes of Dr X and S are clearly in that category, despite their being sufficiently demented to be considered incompetent. Both reflectively endorse these attitudes and want the attitudes to play a particular regulatory role in their lives-- most vividly seen in Dr X's commitment that life without his horses wouldn't be worth living, and in S's preference to avoid an AD and retain decision-making authority. They both look back on these commitments as *their* values.

Though we are interested in *changes* in value via dementia, we think that the attitudes of the moderately demented Dr X and S are clearly relevant to the question of autonomous governance, and we think that assessment should be independent of the content of their attitudes. That is, it would be illegitimate-- though all too easy-- to "read in" competence to these patients because their values are ones we endorse, and to read in incompetence when the values differ from our own. To avoid that mistake, and to say that X and S had attitudes that should be respected, is to say that the valuelike attitudes of post-competent patients deserve the same



We offer evidence that demented patients lacking capacity or competence can retain attitudes and values that imbue their decisions with some autonomy, thereby commanding a degree of moral respect for these decisions. This suggests there are some situations in which demented patients may make healthcare decisions contrary to an advance directive.

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respect. Because patients can change their minds while retaining the capacity to value at this level of competence, we have the same reason to respect *their* valuing as well, and that resists the instructions of the AD.

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