

## Dementia, transformation, and advance directives

Benjamin Lin MS

*Lehigh Valley Health Network*, [benjamin.lin@lvhn.org](mailto:benjamin.lin@lvhn.org)

David A. Merlie

*Lehigh Valley Health Network*

Follow this and additional works at: <https://scholarlyworks.lvhn.org/select-program>



Part of the [Medical Education Commons](#)

## Let us know how access to this document benefits you

---

### Published In/Presented At

Lin, B. & Merli, D.A. (2021). *Dementia, transformation, and advance directives*. Poster presented at Lehigh Valley Health Network, Allentown, PA.

This Poster is brought to you for free and open access by LVHN Scholarly Works. It has been accepted for inclusion in LVHN Scholarly Works by an authorized administrator. For more information, please contact [LibraryServices@lvhn.org](mailto:LibraryServices@lvhn.org).



# Dementia, transformation, and advance directives

Benjamin C. Lin, David A. Merli

Lehigh Valley Health Network, Allentown, Pennsylvania

The increasing age of the population and increasingly early detection of conditions that cause dementia such as Alzheimer's disease in their prodromal stage mean that writing advance directives prior to becoming demented is becoming more common. In this paper we examine the moral authority of advanced directives. Advance directives made by patient can decline medical care for their future incompetent self. When a demented patient lacking capacity expresses a desire to make a healthcare decision that is contrary to that prior advance directive, the status quo is that the advanced directive takes precedence. We examine the authority of advance directives in an important class of dementia cases: those in which patients' current best interests appear to conflict with their past instructions.

## Problem Statement

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

- 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.

- One patient, Dr X, is a retired physician. His dementia caused him to be lost in familiar areas, unable to make sense of what he was doing or where he was going. He planned for suicide--an attitude toward which he has mixed feelings now, saying that his wish "seems very strange now, looking back" but also saying that he would not want to live if his cognitive dementia returned, as this would prevent him from engaging in the activities he loves. (He adds that people of the right temperament and with good support could live happily with dementia.)
- The second patient, S, is a retired engineer who describes his experience of dementia this way:
- "One of the scariest things is - in conversation the sudden... impact [of realizing] I used to know what those words meant, and now I don't. I knew that I had known how to do other things, and the ability had escaped me...I was working in my yard, and I was in a flowerbed that was elevated several feet above the ground, and I had the instant realization that I don't know how to get down. Driving one day - where am I? how 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 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 value-like attitudes of post-competent patients deserve the same 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.

- Our core claim is that the loss of competence does not entail the absence of valuing, caring, or exercise of the will that commands respect in treatment decisions. Interviews with patients who had been cured of dementia in the via successful treatment for normal pressure hydrocephalus reveal that patients retrospectively endorse the continuity of their values throughout their period of dementia. In addition, the quality of these values at the time of dementia seem to be of the appropriate sort to demand respect from the standpoint of autonomy.

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.

## REFERENCES

- Brickman, P, D Coats, and R Janoff-Bulman. 1978. "Lottery winners and accident victims: is happiness relative?" *J Pers Soc Psychology* 36 (8): 917-927.
- Brody, Howard.
- Burley, Justine. 2004. *Dworkin and His Critics*. Wiley-Blackwell.
- Carel, Havi. 2016. *The Phenomenology of Illness*. Oxford: Oxford University Press.
- Carel, Havi, Ian James Kidd, and Richard Pettigrew. 2016. "Illness as transformative experience." *The Lancet* 388: 1152-1153.
- Cox, Harold. 2007. "Normal pressure hydrocephalus: a case report by a physician who is the patient." *Clinical Medicine* 7(3): 296-299.
- Dolan, Paul. 1997. "Modelling valuations for EuroQol, Health States." *Medical Care* 35 (11): 1095-1108.
- Dworkin, Ronald. 1993. *Life's Dominion*. New York: Vintage Books.
- Frank, Robert. 2010. *Luxury Fever*. Princeton University Press.
- Fricker, Miranda. 2007. *Epistemic Injustice*. Oxford: Oxford University Press.
- Gilbert, Daniel. 2006. *Stumbling On Happiness*. New York: Alfred A Knopf.
- Herman, Elizabeth. 2009. "I'll be glad I did it' reasoning and the significance of future desires." *In Philosophical Perspectives* 23.
- Jaworska, Agnieszka. 1999. "Respecting the margins of agency: Alzheimer's patients and the capacity to value." *Philosophy and Public Affairs* 28 (2): 105-138.
- Jaworska, Agnieszka. 2007. "Caring and internality." *Philosophical and Phenomenological Research* 74 (3): 529-568.
- Martyr, Anthony et al. 2018. "Living well with dementia: a systematic review and correlational meta-analysis of factors associated with quality of life, well-being and life satisfaction in people with dementia." *Psychological Medicine*. <https://doi.org/10.1017/S0033291718000405>
- McMahan, Jeff. 2002. *The Ethics of Killing: problems at the margins of life*. Oxford: Oxford University Press.
- Paul, LA. 2014. *Transformative Experience*. Oxford: Oxford University Press.
- Pettigrew, Richard. 2015. "Transformative experience and decision theory." *Philosophy and Phenomenological Research* 91 (3): 1-7.
- Shiffrin, Seana. 2004. "Autonomy, beneficence, and the permanently demented." *In Burley* 2004: 195-217.
- Steinbock, Bonnie, ed. 2007. *The Oxford Handbook of Bioethics*. Oxford: Oxford University Press.
- Ullmann-Margalit, Edna. 2008. "Big decisions: spring, converting, drilling." *Royal Institute of Philosophy Supplement* 58: 157-172.
- Zank, S, and B Leopold. 2001. "The relationship between severity of dementia and subjective well-being." *Ageing and Mental Health* 5(2): 191-196.

© 2018 Lehigh Valley Health Network