Published in final edited form as:

Lancet Psychiatry. 2017 November ; 4(11): 830. doi:10.1016/S2215-0366(17)30373-5.

No doubts about dementia advocacy

William T Hu

Department of Neurology, Emory University, Atlanta, GA 30329, USA

In his Comment in *The Lancet Psychiatry*, Robert Howard¹ bravely shared his personal questions on the diagnostic uncertainty of some dementia advocates, and I suspect others might be similarly perplexed. I would like to provide some personal observations from the USA to narrow the gap between the purely medical model of dementia and the lived experience of Persons with Dementia.

Howard is correct that dementia advocates often have younger symptom onset (<65 years), and I note that they also have better health, education, and social support, and are wealthier than the average individual with dementia. Serving as an advocate while ill is a luxury many cannot afford. It is not surprising that advocates were often leaders in their professions (eg, executives, professors). Additionally, it should come as no surprise that for individuals with dementia acting as an advocate comes with its own costs, both personal (eg, confusion at unfamiliar locations, family discord, irregular schedules) and financial (eg, paying for car service, higher airfares for direct flights, longer hotel stays to aid re-orientation, need for travel companions). Thus, dementia advocacy is a form of John Henryism (named after the American folklore figure who died victorious after showing his superior prowess over a machine), and the advocates' health can be made worse by the persistent curiosity of dementia professionals into their abilities.

Moreover, cognitive assessment in public settings is not valid or accurate. Because advocates are few in number, the diagnostic doubt described by Howard falls within the margin of error for any dementia test. As a result of this margin of error, and additional ethical reasons, the American Psychiatric Association discourages so-called diagnosis-by-soundbites.² In the USA, I have personally witnessed the longitudinal decline of several dementia advocates, and often find a need to defend their dignity and rights in environments that make little accommodation for their cognitive decline. Additionally, Dementia Alliance International has put together recommendations³ to optimise accessibility for Persons with Dementia at conferences and events, although few organisations have adopted them.

Finally, substantial stigma exists that is associated with the reliability and trustworthiness of Persons with Dementia. The reluctance to believe these individuals contributes to crimes in nursing homes in the USA,⁴ and is reinforced by the clinical practice of assessing them only for their deficits and not for their residual functions. If we re-imagine dementia through the rehabilitation principles of impairment and disability, dementia advocates' exceptional courage to speak up is a form of resilience and not a contradiction to their disease. Dementia advocates thus remind me of Paralympic athletes, whose visible disabilities are never in doubt despite great personal accomplishments.

I applaud Howard for starting a much-needed conversation, but meaningful engagement must extend beyond Persons with Dementia feeling like curios and sideshows. Dementia advocates are emerging in high-income nations (eg, the North American Dementia Action Alliance) and in low-income and middle-income nations (eg, the 2017 Alzheimer's Disease International African Regional Conference), and clinicians, scientists, and policymakers should build new partnerships with those individuals to bring forth innovation in curing and caring for Persons with Dementia.

Acknowledgments

WTH volunteers on the Scientific Advisory Board of the North American Dementia Action Alliance, reports personal fees from the Alzheimer's Association, AARP Inc., and Locks Law Firm, grants from Avid Pharmaceuticals and the Dementia Spotlight Foundation, and non-financial support from Hoffman-LaRoche and Abbvie, outside the submitted work. Additionally, WTH has a patent US 9618522 B2 Diagnostic testing in dementia and methods.

References

1. Howard R. Doubts about dementia diagnoses. *Lancet Psychiatry*. 2017; 4:580–81. [PubMed: 28499729]
2. American Psychiatric Association. The principles of medical ethics. Arlington, VA: American Psychiatric Association; 2013.
3. Dementia Alliance International. Supporting and accommodating people with dementia at professional conferences and other events. Dementia Alliance International; 2016. https://www.dementiaallianceinternational.org/wp-content/uploads/2016/10/Supporting-and-Accommodating-People-with-Dementia-at-Conferences-and-Other-Events_2016.pdf [accessed Sept 4, 2017]
4. Ellis, B., Hicken, M. [accessed Sept 4, 2017] Sick, dying, and raped in America's nursing homes. 2017. <http://edition.cnn.com/interactive/2017/02/health/nursing-home-sex-abuse-investigation/>