

COMMENTARY

Personhood, dementia literacy, and the causes and consequences of Alzheimer's disease fear

Stephen Post, the well-known US Professor of Bio-medical Ethics, once commented that: "Human beings are much more than sharp minds, powerful rememberers and economic successes" and "that the value of a human being is not diminished by even profound cognitive decline" (Post, 2000, p. 5). He argued that many of us live in hypercognitive cultures that place undue emphasis on rationalism and economic productivity to reflect the worth of human life, and sadly this preoccupation can relegate a person with dementia to the status of social outcast, unwanted, and worthless. Post claimed that it is these hypercognitive values so prevalent in Western society that add stigma to dementia and cause many of us to fear Alzheimer's disease (AD) beyond all other conditions.

While a consensus exists that dementia provokes fear and in some societies, AD is one of the most feared conditions of late life (Bystad *et al.*, 2016), the meaning of this fear is not well understood, nor has it been extensively researched and analyzed. Is fear of AD associated with the fear of its symptoms, such as memory loss and physical, social, behavioral, and cognitive decline? Or is it a fear of being "othered" and labeled with a stigmatizing condition that most people want to avoid and refrain from talking about? For the late Terry Pratchett, both sets of fears were profound. In fact, Pratchett was unsure which for him was worse, having AD or knowing that he had AD (Pratchett, 2015) such were the fear and stigma experienced.

Are there differences cross-nationally in how dementia is framed and understood? Given how dementia causes a disconnect between past and future, can a person diagnosed still have a meaningful existence by living in the present or living only in the past? Is there an association between knowledge and fear and how can fear be used constructively by governments to promote health behaviors that may reduce the risk of developing dementia? To date, several of these questions remain unanswered.

It is for this reason that this new paper (Werner *et al.*, 2020) titled: "Fear about Alzheimer's disease among Israeli and German laypersons, persons with Mild Neurocognitive Disorder and their relatives: A qualitative study" makes a welcome contribution to the dementia care literature. The paper is based on a

cross-national comparative study, designed to address the question: What are the main perceptions and experiences of "dementia fear" among different groups of people? It draws on a convenience sample of 130 people and aims to build an empirical basis to understand how sociocultural attitudes may or may not differ across countries. For its conceptual framework, it uses Hofstede's theory of uncertainty avoidance. A thematic content analysis is undertaken. Not surprisingly two overarching themes are identified as being common to all groups, namely fear of developing AD and fear of the stigma surrounding AD.

Interestingly while one of the papers' key findings is that "AD fear" is common among different groups and across different countries, the study also identifies some unique fears pertinent to specific stakeholder groups. These include the fear of meeting people with AD; becoming a family caregiver; the impact that AD has on other family members; and losing one's sense of self-determination and autonomy. In Israel, some participants were fearful of encountering people with AD, presumably because of the expectation that they would exhibit unpredictable behavior. Israeli people with a mild neurocognitive disorder (MND) along with family members also expressed a fear about the impact AD would have on other family members. In contrast in Germany, laypeople and those with MND had concerns about how AD might result in the loss of autonomy. Curiously in this exposition of "AD fear", no participant talked about the fear associated with having to move from home into a nursing home because of the condition; a fear that many older people experience.

A novel aspect of this study is the way in which focus groups and semi-structured interviews are used to tease out factors likely to trigger AD fears. Three factors are identified, namely: (i) cognitive deterioration as reflected in memory problems and poignantly articulated by some study participants who had an MND; (ii) the absence of a cure for AD, an illness often compared with cancer; and (iii) family history. Regarding the latter, the narratives reveal only a mediocre understanding of the role genes play in contributing to AD from: *If you have someone in your family with dementia, you realize that it also increases your chances [of developing it].*

to: “Is [dementia] genetic? Just something we wait for...? Because if it is, then it would be terrible for the kids. Then they would think: ‘It will eventually happen to me.’ [...] That would be terrible”. A further novel aspect of the study is the identification of coping strategies used by some participants to allay their fears; from prevention strategies such as continued engagement in physical, social, and cognitive activity to the acceptance of a health condition over which some believed they had no control.

Although an abundance of rich qualitative data has been collected in this study, in my view, the work would have been greatly enriched if some of these thought-provoking data had been woven through the manuscript. This would have amplified the voice of the key stakeholders and given the study’s findings more context and conviction. While each testimony cited is important, of particular relevance is the narrative of participants with MND, who are at heightened risk of developing AD and who currently experience symptoms. In the study, they comprise over 20% of all participants. Noteworthy here from the point of view of educational programs is their vulnerability, their appeal for help, their sense of loneliness, isolation, embarrassment, despair, and stigma as portrayed in efforts to cover-up problems experienced lest they be ridiculed or as one participant stated: {being} “put in the dunce’s corner”.

Cross-national studies are difficult to conduct especially when countries differ significantly in population size (Germany’s population is 10 times that of Israel’s) and where language and cultural differences exist. Therefore, the authors of this paper must be commended for their effort and rigor. Despite such differences, Germany and Israel provide a useful platform for comparison. Both countries are at the cutting edge of Western medical progress, with well-developed social healthcare systems and both countries have been instrumental in tackling the challenge of dementia. For example in 2013, Israel developed a national dementia strategy, while the German Ministry of Health and Ministry for Social Affairs launched an “Alliance for people with dementia” in 2012. The latter provides a platform to develop initiatives and provides information on dementia care.

Yet as noted by the authors of this paper, Israel and Germany reflect divergent and opposing bioethical regulations and policy processes. For example, in end-of-life decisions, Germany is more permissive than Israel. It permits passive euthanasia if a person so desires and mandates that doctors follow advanced directives strictly, irrespective of how and when they were composed. In contrast, Israel allows passive euthanasia but only under very strict conditions, and advanced directives are strictly regulated regarding format and registration (Raz and Schickantz, 2016). These differences

might suggest that German people would be less concerned about the potential loss of autonomy rights arising due to developing AD given the more person-centered mental health legislation available, but curiously this was not the case.

“Dementia literacy” refers to knowledge and beliefs about dementia that can assist in its recognition, management, and prevention (Low and Anstey, 2009), but knowledge and understanding of dementia remain low in many countries (Cahill *et al.*, 2015). Given that up to 40% of all dementias may be preventable (Livingston *et al.*, 2020), developing dementia health literacy in the community, especially communicating knowledge about lifestyle choices, risk reduction, and primary prevention is highly desirable. In fact, raising awareness of dementia and improving the public’s understanding of primary prevention and risk reduction is a major goal of most countries dementia strategies (WHO, 2017). Developing dementia health literacy will also help to reduce stigma and cultivate more positive attitudes. I would have liked to see this paper expand on ways in which improvements in “dementia literacy” can be cultivated and achieved in society and the most appropriate channels through which knowledge and information about dementia can be communicated.

The media is a powerful influencer and agent for communicating knowledge about dementia to the public (Gerritsen *et al.*, 2014). However, media portrayal of dementia is often imbalanced: journalists tend to embrace sensational language as it sells news fast and often the language they use reinforces alarm and terror. Dementia is regularly referred to as a “thief”, the person is a “shell of her former self”, prevalence rates are “tsunamis”, and caregivers are the “hidden victims”, “burdened” by the role. This tragedy discourse does little to promote the dignity and personhood of the individual living with the condition. Journalists need to be better educated about dementia. Public broadcasting initiatives must create communication channels that demonstrate empathy and solidarity with people who have dementia and their family members (O’Shea, 2020) rather than distancing the individual and attacking their self-worth.

The final point not addressed in this study is that dementia is often equated with total incapacity and the inability to engage in any decision-making: misconceptions that can also engender fear. Such misconceptions can also relegate the individual to the status of nonperson or passive recipient of care. Across the world, there are many artists, painters, musicians, and so on who have continued to produce excellent works despite their diagnosis. The late Terry Pratchett continued to write best-selling novels and make TV documentaries after his diagnosis of AD. His writing and advocacy work helped raise

awareness, attracted research funding, and showed the world how people can live well with dementia. Yet, how well a person lives with the condition is influenced by a broad range of factors, biological, social, psychological, economic, and cultural.

Kitwood (1997) argued that the decline associated with dementia (AD) occurred not only because of damage to the brain caused by dementia, but also because of the erosion of personhood caused by a “malignant social psychology”. The latter was defined by him as a very harmful care environment that can undermine a person’s humanity. AD can be an extremely frightening condition and it may be all the more terrifying if our negative attitudes about the condition are inadvertently communicated to the person experiencing the symptoms. Through our behavior, language, and interactions, all of us can play a key role in either supporting the person to live well with AD or conversely hindering that person’s subjective experience. We have a lot more in common with a person living with AD than we have not (Sabat, 2019) and there is an onus on each of us to come to terms with our fears about our future frailty and mental instability. We must unite in solidarity to create an inclusive world for all of us to live well in whether we have AD or not.

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References

Bystad, M., Grønli, O., Lilleeggen, C. and Aslaksen, P. M. (2016). Fear of diseases among people over 50 years of age: a survey. *Scandinavian Psychologist*, 3, e9.

- Cahill, S., Pierce, M., Werner, P., Darley, A. and Bobersky, A.**, 2015. A systematic review of the public’s knowledge and understanding of Alzheimer’s disease and dementia. *Alzheimer Disease & Associated Disorders*, 29, 255–275.
- Gerritsen, D. L., Kuin, Y. and Nijboer, J.** (2014). Dementia in the movies: the clinical picture. *Aging & Mental Health*, 18, 276–280.
- Kitwood, T.** (1997). *Dementia Reconsidered: The Person Comes First*. Buckingham: Open University Press.
- Livingston, G. et al.** (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *The Lancet*, 396, 413–446.
- Low, L. F. and Anstey K. J.** (2009). Dementia literacy: recognition and beliefs on dementia of the Australian public. *Alzheimer’s & Dementia*, 5, 43–49.
- O’Shea, E.** (2020). Remembering people with dementia during the COVID-19 crisis. *HRB Open Research*, 3, 1–4.
- Post, S.** (2000). *The Moral Challenge of Alzheimer’s Disease: Ethical Issues from Diagnosis to Dying*. Baltimore, MD: John Hopkins University.
- Pratchett, T.** (2015). A Butt of my Own Jokes: Terry Pratchett on the Disease that Finally Claimed Him. *The Guardian*, March 15th.
- Raz, A. and Schicktanz, S.** (2016). *Comparative Empirical Bioethics: Dilemmas of Genetic Testing and Euthanasia in Israel and Germany*. Switzerland: Springer International Publishing.
- Sabat, S. R.** (2019). ‘Looking beyond pathology: People with dementia can teach us about our shared humanity’. *A symposium on Dementia and Human Rights*. Trinity College Dublin, November 8th.
- Schicktanz, S., Rimón-Zarfaty, N., Raz, A. and Jongasma, K.** (2018). Patient representation and advocacy for Alzheimer Disease in Germany and Israel. *Journal of Bioethical Inquiry*, 15, 369–380.
- Werner, P., Ulitsa, N., Shepheth, D., Abojabel, H., Alpinar, S. and Schicktanz, S.** (2020). Fear about Alzheimer’s disease among Israeli and German laypersons, persons with Mild Neurocognitive Disorder and their relatives: a qualitative study. *International Psychogeriatrics*, doi: [10.1017/S1041610220003397](https://doi.org/10.1017/S1041610220003397).
- World Health Organization.** (2017). *Global action plan on the public health response to dementia 2017–2025*. Geneva: World Health Organization.