

## Ethics Response

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# Patient Preferences May Be Indicative of Normative Issues in Dementia Research

Cynthia Forlini\*

*ARC DECRA Research Fellow, Centre for Values, Ethics and the Law in Medicine, The University of Sydney, Sydney, Australia*

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**Abstract.** Robillard and Feng highlight incongruence between patient preferences and the procedural aspects of research ethics as they relate to protocols for dementia research. Their findings break ground for a reassessment of how research ethics, researchers, and participants (including patients and caregivers) approach participation in dementia research. However, it is unclear whether patient preferences may also herald a normative gap between how dementia research is being conducted and how it should be done. This response uses one of Robillard and Feng's findings to illustrate how descriptive empirical data might be reinterpreted into normative questions that reframe current practices in the context of dementia research.

**Keywords:** Alzheimer's disease, dementia, empirical ethics, ethics, neuroethics, normative ethics, research ethics

Robillard and Feng call for research ethics policy and practice to incorporate the needs, wishes, and values of patient communities. The call is inspired by their findings from a patient engagement initiative that highlighted incongruence between patient preferences and the procedural aspects of research ethics as they relate to protocols for dementia research [1]. Robillard and Feng's foray into the empirical investigation of the perspectives of the dementia patient population, often a challenging group to engage, has broken ground for a much-needed reassessment of how research ethics, researchers, and participants (including patients and caregivers) approach participation in dementia research.

Accompanying the empirical line of inquiry should be reflection upon the significance of patient

preferences as the impetus for changing dementia research policy and practice. Robillard and Feng's findings evoke the perennial challenge of using empirical data that describe what *is* to inform what *ought* to be done [2]. Indeed, preferences of dementia patients seem to collide with research ethics on a descriptive level that, in certain instances, may hinder participation of dementia patients in research. However, it is unclear whether a similar argument might be made on normative grounds. Patient preferences may herald a normative gap between how dementia research is being conducted and how it should be done. For example: Who is benefitting from the fruits of dementia research? What is the appropriate level of side effects for this population? What value does voluntary and informed consent have in the context of cognitive impairment? A normative lens may help to see beyond the perceived limitations of research ethics guidelines highlighted by patient preferences and focus on the principles, values and practices that are currently guiding dementia research.

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\*Correspondence to: Cynthia Forlini, PhD, Level 1, Medical Foundation Building K25, The University of Sydney, Camperdown, NSW 2006, Australia. Tel.: +61 286275354; E-mail: cynthia.forlini@sydney.edu.au.

Robillard and Feng's finding that dementia patients would like to maximize opportunities for research participation shall serve as an illustrative example of the normative approach I suggest. A descriptive analysis of dementia protocols in the Netherlands by Jongsma et al. showed that dementia studies represent neither the average dementia patient nor the heterogeneity in the presentation of dementia (e.g., type and rate of progression) [3]. Alzheimer's disease accounts for 41% of dementia cases [4] and was represented in 88% of studies while vascular dementia accounts for 32% of cases [4] but corresponded to only 4% of studies. Additionally, studies avoided patients with advanced stages of dementia living in care facilities, which set the focus of the research on mild to moderate impairment. One part of addressing patient preferences for research participation is to note that participants cannot be recruited to studies that simply do not exist. Another component is to ask whether more diverse dementia patients *should* be readily integrated in research. This question tends toward normative inquiry. Though initially identified as a limitation in research ethics guidelines on participant recruitment, the preference to participate more frequently in research might be reinterpreted as exclusion of dementia patients from research or perhaps even the overburdening of certain groups of patients. These reinterpretations both go toward addressing normative issues such as what an appropriate level of research participation would be for the dementia patient population(s).

The example of research participation can be taken further still. Researchers working on aging-related protocols have reported difficulties in accessing dementia patients with advanced cognitive impairment due to barriers from human research ethics committees [5]. Pachana et al. posit that these barriers reflect the vulnerability ascribed to aging individuals by research ethics committees through the lens of ageism and stereotyping of the loss of cognitive capacity in older age [5]. Thus, research ethics committees "may unwittingly put up barriers to conducting research on older populations with the intention of protection from harm" [5 p. 705] and unnecessarily preclude their participation [6]. This approach reinforces a model of autonomy based on the concept of *personhood* defined by Kitwood as "a standing or status that is bestowed upon one human being by others in the context of particular social relationships and institutional arrangements" [7 p.7]. In the context of research ethics, personhood ignores the complicated, contextual, and changing nature of

autonomy in dementia patients [8] that may affect the recruitment, consent, and data collection processes. It has been suggested that dementia practice and research integrate *citizenship* to reflect the voice of dementia patients [6]. Through citizenship, dementia patients might move beyond a bestowed status (personhood) toward a practice which repositions them as active agents within their communities. Robillard and Feng's findings indeed resonate with the citizenship model. Perhaps more than a preference to participate in research, dementia patients are expressing the need for a culture shift in both practice and research that (1) recognizes how their autonomy changes as dementia progresses and (2) integrates the principles of both personhood and citizenship, where applicable.

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