

Dementia, vulnerability and well-being: the implications of alternative accounts

Research team

Professor John O'Neill, Professor of Political Economy, University of Manchester

Professor Suzanne Skevington, Professor of Health Psychology, University of Manchester

Annie Austin, doctoral researcher, Cathie Marsh Institute for Social Research, University of Manchester

Background

In 2015 there will be 850,000 people living with Dementia in the UK, rising to 1 million by 2025 (Alzheimer's Society, 2014). In the context of an ageing population, supporting the well-being of people with dementia represents a central – and growing – challenge to society. The concepts of well-being and vulnerability are widely contested in a number of areas of public policy. Competing concepts underpin different approaches to caring for people with dementia, and have competing implications for policy and practice. This project will build on previous work of the applicants on well-being, vulnerability and dementia (e.g. Trigg et al 2007, Lindley et al 2011, Austin 2014) bringing together philosophical, health science and social scientific disciplines. It aims to examine the different dimensions of well-being and vulnerability to develop an approach to both that can underpin good ethical practice and policy.

Well-being

The concept of 'well-being' is a contested one. For example, some see well-being as a particular subjective state such as 'happiness' (e.g. Layard 2005). In contrast, others see well-being as multi-dimensional and as encompassing a range of valuable functionings - things a person can be and do in their lives – and capabilities to achieve these functionings (Sen 1993, Nussbaum 2000). These 'objective' accounts can be extended to conceptualise well-being as having a narrative structure (O'Neill 2008), involving ideas of self- and social-identity, and it is these ideas that are often at the heart of discourses around dementia and care. For example, the National Dementia Declaration (Dementia Action Alliance 2010) focuses on each individual's need for access to a support network that suits their unique and multi-faceted needs, and supports their individual and social identities. Similarly, the Alzheimer's Society's Dementia Friendly Communities programme focuses on social inclusion and well-being in all aspects of life, from public transport and cafes to participation in creative arts and leisure activities (Telfer 2014).

The definition of well-being that is employed - or tacitly assumed - by individual carers and organisations determines how care is designed, implemented and evaluated. An example of an approach to dementia care based on a subjective-state account of well-being is the Specialised Early Care for Alzheimer's (SPECAL) approach from the Contented Dementia Trust (see James 2008). This approach raises many ethical questions and has been heavily criticised for its primary focus on cultivating the 'right' subjective state in a person with dementia, and the methods advocated to achieve this. This example highlights the importance of analysing the fundamental assumptions and concepts that provide the basis of care practices.

Vulnerability

A capabilities approach to well-being can also be used to ground a wider understanding of vulnerability. A central argument against simply using a resource metric for well-being is that resources are differentially converted into well-being. A distinction can be drawn between three kinds of conversion: personal, social and environmental (Sen, 2009). For example, the resources a disabled person will require to realise the same opportunities for mobility will be greater than that of an able-bodied person. Personal physical handicaps, social and institutional prejudices, and the physical layout of the built environment will all limit in different ways the conversion of resources into mobility.

The obverse of the differential conversion of resources into gains in well-being is the differential conversion of a condition or events into losses in well-being. Vulnerability can be understood in terms of the degree to which, and likelihood that, an event or condition converts into losses in well-being. Correspondingly, policy can target different conversion factors (Lindley and O'Neill 2012): it might target the physical disability through medical interventions; it might target the environmental conversion factors through standards that improve the built environment to enable access. However, as social models of disability have stressed, the social sources of disadvantage must also be addressed through policies that aim to change institutional norms and prejudices. Much of the existing work in dementia care has been about addressing the personal conversion factors – though medical interventions – and the environmental conversion factors through both changes to homes or through devices that allow people who wander to be tracked. Until recently, social conversion factors were much less emphasised, even though they are central to many losses in well-being. The recent focus on dementia friendly communities is in part addressing this social dimension of vulnerability.

Research plan

The aim of this project is to develop an approach that will allow the full range of the dimensions of well-being and vulnerability to be addressed. The research will analyse the accounts of well-being and vulnerability assumed by different approaches to caring for people with dementia, and draw out the implications of these for policy and practice. Given this aim, the research comprises two main streams:

1. Desk-based review, including literature search, document analysis and a small number of targeted telephone interviews
2. Workshop with key Manchester-based actors on dementia

Outputs

- Consultative workshop with key actors
- Final report, including scope for future larger interdisciplinary research proposal extending beyond Manchester and brings together humanities, social scientific and medical perspectives on well-being and dementia
- 1 journal article, to be targeted at the *Journal of Medical Ethics* or related publications

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