
Article:
Austin, A. orcid.org/0000-0003-0128-7018 (2018) Living well with dementia together : affiliation as a fertile functioning. Public Health Ethics, 11 (2). pp. 139-150. ISSN 1754-9973

https://doi.org/10.1093/phe/phw045

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Article accepted for publication 1/11/16
Public Health Ethics, DOI: 10.1093/phe/phw045

Living Well with Dementia Together: Affiliation as a Fertile Functioning

Abstract

Justice requires that public policy improve the lives of disadvantaged members of society. Dementia is a source of disadvantage, and a growing global public health challenge. This paper examines the theoretical and ethical connections between theories of justice and public dementia policy. Disability in general, and dementia in particular, pose important challenges for theories of justice, especially social contract theories. First, the paper argues that non-contractarian accounts of justice such as the Capabilities and Disadvantage approaches are better equipped than their contractarian counterparts to analyse issues of justice and dementia. Second, using a capabilities framework, I analyse original empirical data from qualitative interviews and discussion groups with health and social care professionals. The paper concludes that social connection is a 'fertile functioning' – a multiplier of advantage that enables people to live well with dementia together – and should therefore be a priority for public dementia policy.

Keywords: Dementia; Disadvantage; Justice; Capability; Social Contract

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Introduction

Dementia is defined by the World Health Organisation (WHO) as "a syndrome, usually of a chronic or progressive nature, caused by a variety of brain illnesses that affect memory, thinking, behaviour and ability to perform everyday activities" (WHO 2015). It represents a growing global public health challenge: in 2015 there were an estimated 47.5 million people worldwide with dementia (WHO 2015), with this number expected to double every 20 years (ADI 2015). As populations age, governments across the world have begun to develop dementia policy strategies: examples include the *National Alzheimer's Project Act* (2011) in the USA; the *National Framework for Action on Dementia* (2015) in Australia; and the UK's National Dementia Strategy (2009): *Living Well with Dementia*.

Dementia is a source of multiple disadvantages. In 2010, the United Nations (UN) established a working group on ageing, to address the gaps in existing human rights standards in relation to older people:

> "Throughout the world, large numbers of older persons face challenges such as discrimination, poverty and abuse that severely restrict their human rights and their contribution to society" (UN 2012).

The disadvantages faced by older people in general are likely to be compounded for older people with dementia, since cognitive impairment represents an additional 'layer of vulnerability' (Luna 2014). Justice demands that public policy prioritise the well-being of the disadvantaged; therefore, improving the lives of people with dementia should be viewed not only as a global health priority, but as an urgent matter of social justice.

Disability in general poses important challenges for theories of justice, particularly social contract theories. Some central features of contractarian theories come under severe strain in the context of disability. This paper argues that, to accommodate the moral claims of disabled people, it is necessary to appeal to non-contractarian approaches to justice; examples include Nussbaum's (2007) account of justice as equality of Capability, and Wolff and de-Shalit's (2007) analysis of Disadvantage. These approaches aim to include disabled people as primary subjects of justice, making room for disability at the conceptual stage, rather than leaving it aside as an 'outlier' or 'executive' issue, as many social contract theories do (e.g. Rawls 1999).

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This paper focuses on dementia as one particular kind of disability, and connects theories of justice with the public policy goal of improving the lives of people with dementia. The first section summarises the challenges posed by disability to social contract theories of justice, and shows how alternative, non-contractarian theories overcome those challenges. The second section sets out a conceptual framework for connecting dementia, justice and public policy. The third section uses a capabilities framework to analyse the results of qualitative interviews and discussion groups with health and social care professionals about living well with dementia. The analysis shows that affiliation is a 'fertile functioning' – a multiplier of advantage - for people living with dementia. The final section concludes, therefore, that supporting the social relationships of those living with dementia should be a priority for public dementia policy.

Justice, Disability and Dementia

Among the diversity of approaches to justice, social contract theories stand out as particularly influential. Social contract theories are based on the premise that societies are organised by a consensual agreement between citizens to cooperate with one another for mutual advantage (Hobbes 1996; Rawls 1999). In his seminal work, Rawls conceives of the contracting parties as free, equal and autonomous (p. 515). They are in symmetrical power relationships with one another, and "are assumed to take no interest in one another's interests" (p.147) - they have their own private ends that are either independent or competing but "not in any case complimentary" (p.521). Further assumptions are made about the rationality of the contracting parties, who make life plans and decisions based on "careful consideration" of "all the relevant facts" and their consequences (p. 417). This Kantian conception of personhood takes reason to be the source of the dignity of the person: on this account, a person's status as equal and deserving of respect as an end in herself is grounded in her capacity for rational agency (Kant 1999).

The logical structure and assumptions of classical social contract doctrine exclude people with some types of impairment from participation in society as primary subjects of justice (cf. Sen 2004; Silvers and Francis 2005; Nussbaum 2007). The remainder of this section provides a brief summary review of objections to contractarianism, and how they apply in the context of disability.

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The first difficulty lies with the idea that mutual advantage is the goal of social cooperation and reciprocity. People with physical and cognitive impairments may be less able to cooperate on an equal basis with others; relationships between people with impairments and the social group are likely to be asymmetric in terms of mutual advantage, especially when 'mutual advantage' is conceptualised in terms of economic productivity.

A second difficulty concerns the contractarian account of the autonomous pursuit of one's private ends. This assumption fails to acknowledge the shared nature of many ends, and the relationships of solidarity, love, care and dependence within which people strive to live in accordance with their conceptions of the good. Neediness and dependency are inalienable features of human existence (Reader 2007). Asymmetric dependence is a feature of childhood and (often) old age, and occurs in the context of temporary illness as well as permanent impairment. Dependency does not set children and older, ill or disabled people apart from other people; rather, dependency is a spectrum onto which all human beings fall (Nussbaum 2007).

A third concern with classical social contact theory arises in relation to the requirement that the contracting parties meet the demands of an idealized rationality that is narrow and overly demanding (Dresser 1995; Kittay 1997). For example, Jaworska (1999) argues that the ability to reflectively formulate life goals sets the threshold for personhood too high, and excludes people with some types of cognitive impairment, including advanced dementia.

Advocates of a more inclusive social contract theory have argued that a social insurance system could provide the support needed by disabled people to participate in mutually advantageous social cooperation (Becker 2005). It would therefore be strategically beneficial for the contracting parties to agree to such an insurance system. Similarly, those choosing the principles of justice from behind a 'veil of ignorance' (Rawls 1999:12) would, in theory, incorporate considerations around disability, since this could be their fate when the veil is lifted. However, these arguments still fall short. By retaining the requirement of idealized rational agency, people with cognitive impairments are excluded as contracting parties themselves: they remain objects and not subjects of justice. As well as failing to meet the objection from idealized rationality, these alternative accounts also maintain individualistic assumptions about the nature of 'mutual advantage' and the autonomous pursuit of individual ends.

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In summary, classical social contract doctrine is grounded in assumptions that create difficulties in accommodating disability, namely, the prioritisation of independence and individual rational agency, and a corresponding failure to recognise that dependence and 'patiency'i (Reader 2007) are inalienable features of human existence. On such demanding criteria for citizenship and personhood, many disabled people would be ineligible as primary subjects of justice. These are simplifying assumptions, made in pursuit of theoretical and logical clarity. However, ignoring the relational basis of personhood risks making the space between ideal-type and real-world social justice too wide to bridge.

Non-contractarian approaches to justice and disability

Given these features of the classical contractarian theory of justice, alternative accounts are needed for thinking well about justice and disability, and to provide a sound basis for ethical policy and practice. This section focuses on two such alternative accounts: the Capabilities Approach (Sen 1985; Nussbaum 2000) and the Disadvantage approach (Wolff and de-Shalit 2007).

The Capabilities Approach

The Capabilities Approach (CA) is a broad conceptual framework for the analysis of well-being and social justice. It departs from the tradition of welfare analysis that focuses on income and resources, and expands the definition of well-being to cover a plurality of valuable 'functionings' that people can achieve in their lives (Sen 1985). The CA distinguishes between functionings - the 'beings and doings' that a person achieves - and capabilities - the freedoms she has to achieve valuable and valued functionings. Capabilities are determined not only by the resources a person possesses, but also her personal characteristics and the social, political and material environment in which she lives (Sen 1985). 'Refined functionings' - the combination of capability (freedom) and functioning (achievement) – have been argued to provide the most complete informational basis for the evaluation of well-being and social justice (Sen 1992; Fleurbaey 2006). This is an important nuance in the context of dementia and other cognitive disorders that affect a person's capacity for reasoned choice and agency.

The conceptual apparatus of the CA can accommodate disability issues due to three distinguishing features. First, the CA modifies the classical assumption of social cooperation for mutual benefit. Based on an Aristotelian conception of the fundamental sociality of the person, the CA expands the concept of 'mutual advantage' to include benefits based on the assumptions of inter-dependence

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and shared ends, and other-oriented moral sentiments such as compassion, benevolence and altruism (Nussbaum 2007:91). This involves modifying the strong individualistic assumptions of independence and autonomy, and placing relationality at the centre of the human experience: 'No individual can think, choose or act without being influenced in one way or another by the society around him or her' (Sen 2002:80). While Sen endorses normative individualism in relation to the ethical distinctness and moral status of each person, he also defines human beings as 'quintessentially social creatures' with 'multiple affiliations…and different types of societal interactions' (Sen 2002:81). Sociality is a central part of capability, and normative individualism is compatible with recognition of the relational basis of personhood and well-being.

The second distinguishing feature also stems from the CA's Aristotelian account of personhood. While Kantian rationality is transcendental and sets humans apart from other animals, on an Aristotelian conception of personhood, the ability to reason is merely one aspect of a person as a social and political animal; as Nussbaum (2007:159) puts it, far from being contingent on an idealized form of individual rational agency, Aristotelian personhood is constituted, along with a plurality of other elements, by "just garden-variety practical reasoning".ii

The third distinguishing feature of the CA relates to its pluralist and non-resourcist conceptualisation of capability. First, capabilities are defined as plural and incommensurable (Nussbaum 2000:81). Second, people have varying abilities to convert resources (commodities and other primary goods) into valuable outcomes, with physical or cognitive impairment being an important individual-level 'conversion factor' (Sen 1985). It follows from the two features of incommensurability and differential resource conversion that resource-based metrics of well-being are inadequate for capturing the rich plurality of living well, and the complexity of disadvantage.

In summary, the modification of the contractarian assumptions of (1) social cooperation for mutual advantage, (2) independent autonomy and (3) personhood as individual rational agency, plus its rejection of 'resourcism', enable the CA to accommodate considerations around disability in its basic concept of justice.

Disadvantage

Wolff and de-Shalit's (2007) account of Disadvantage extends the capability approach to well-being and social justice. Like the CA, the Disadvantage approach distinguishes between achieved functionings and the wider set of hypothetical capabilities available to a person, given her personal

characteristics and resources, and the environment in which she lives. Wolff and de-Shalit add an additional analytical dimension, characterising functionings as 'secure' or 'insecure'. A functioning is insecure if a person has a lower probability of sustaining that functioning due to exceptional involuntary risk and vulnerability, or because achieving the functioning entails (or will in future entail) sacrifice in relation to other important functionings (Wolff and de-Shalit 2007:72).

The Disadvantage account is also based on a pluralist, non-resourcist conception of well-being. This pluralism is at the heart of the central problem that the Disadvantage project sets out to address: assuming that improving the lives of the most disadvantaged members of society is a requirement of justice and a pressing priority for public policy, how can the least well-off be identified on a pluralist account of disadvantage? For example, is a person living in poor housing worse off than a person in poor health? Given the incommensurability of the goods that constitute a good human life, and the complexity of disadvantages that constitute being badly-off, a single index of disadvantage is impossible. How then should the least well-off be identified? This is known as the 'indexing problem'.

Dementia, Disadvantage and Justice

The indexing problem relates to the problem of identifying 'the most disadvantaged' group on a pluralist account of well-being. To solve the indexing problem, Wolff and de-Shalit (2007:103) introduce the concept of "clustered disadvantage". In order to identify the worst-off in society (and therefore show where the requirements of justice are most urgent) a 'robust social ordering' is required – that is, a way of identifying the worst-off that is robust to the different weightings that might be given to different categories of disadvantage.

The proposed solution rests on the observation that disadvantage tends to appear in clusters: people who are badly off in one important category of functioning also tend to be badly off in other categories. The ideas of 'fertile functionings' and 'corrosive disadvantages' help explain how and why disadvantages cluster. A corrosive disadvantage causes and compounds other disadvantages, while a fertile functioning is a functioning that has positive spill-over effects in other areas of functioning (Wolff and de-Shalit 2007: ch. 7-8).

Assuming broad agreement on what the important functionings are, the tendency for disadvantages to cluster provides a legitimate foundation for a robust social ordering that allows the identification of the worst-off.

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The assumption of consensus around the most important functionings is a large one. Wolff and de-Shalit use Nussbaum's (2000) list of Central Capabilities as their conception of what matters most in a human life. Nussbaum frames her list as an overlapping consensus about a set of basic political entitlements, developed through philosophical reasoning, refined through empirical experience, and specified at a level that is abstract enough to be compatible with the principles of political liberalism (Nussbaum 2007). The ten 'Central Human Functional Capabilities' are specified in the broad domains of: 'Life'; 'Bodily Health'; 'Bodily Integrity'; 'Senses', Imagination and Thought'; 'Emotions'; 'Practical Reason'; 'Affiliation'; 'Other Species'; 'Play' and 'Control over one's Environment'.

The Disadvantage approach suggests that "de-clustering disadvantage" should be an intermediate end for public policy. By breaking the causal connections between different types of disadvantage, a society would effectively eradicate the category of 'worst-off overall', and instead be able to concentrate on the final end of eliminating disadvantage in specific spheres of justice. The 'de-clustering' approach breaks down the complexity of disadvantage, clearing the way for public policy to target specific disadvantages among particular vulnerable groups, and redress unjust inequalities in secure functioning.

Dementia-related clustered disadvantage

Dementia is a source of clustered disadvantage in terms of people's ability to achieve secure functionings. The symptoms of dementia typically involve 'a gradual decline in [the] ability to understand, remember, reason, communicate and use learned skills' (AS 2010). Many people with dementia have co-occurring physical impairments that compound the effects of cognitive impairment. Dementia is also a stigmatised condition, and social exclusion is a widely reported side-effect of a dementia diagnosis (Bartlett and O'Connor 2007, ADI 2012). Older people, who are more likely to have dementia, are also more likely to have insufficient income to heat their homes adequately (Walker and Day 2012) and have lower ability to buy nutritious food due to budgetary constraints and mobility issues (Dowler and O'Connor 2012). There are social gradients in the well-being of people with dementia, with those of lower socio-economic status suffering further disadvantage in multiple domains, due to inequalities in access to healthcare, material and social resources and education (Basta et al 2007; Rait et al 2010).

The clustering of dementia-related disadvantage has two related implications. First, it allows the identification of people living with dementia as among the worst-off in society. Second, this implies

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that a priority for dementia policy should be the de-clustering of dementia-related disadvantage. It follows that public dementia policy ought to seek to identify fertile functionings that would help to de-cluster dementia-related disadvantage, and enable the effective targeting of separate spheres of disadvantage, leading to real improvements in the well-being of people living with dementia.

Moving from theory to the details of how disadvantage can be de-clustered in practice is an empirical question. To identify fertile functionings, Wolff (2009:221) states that "we need to appeal to social science."

Living well with dementia: An appeal to Social Science

After a description of methods, this section presents an analysis of findings from primary qualitative research with professionals working in dementia care policy and practice.

Methods

Empirical research was conducted with experts involved in planning, providing, evaluating and budgeting dementia care. Fieldwork took place in the UK in July 2015, and consisted of discussion groups and telephone interviews involving 15 participants in total. The central aim of this qualitative research design was to gather rich, in-depth insights to illuminate and add content to a social capabilities model of living well with dementia. This 'expert evidence' represents one part of a larger programme of research that, in its next stages, will include people living with dementia and their families.

Participants were recruited through the Manchester Institute for Collaborative Research on Ageing (MICRA) network of over 1,200 policy-makers, practitioners, academics and members of the public in the UK. An invitation was emailed to a subset of the network, selected on the basis of their job title and organisation, and their role as decision-makers or practitioners in dementia care. Participants represented three local government authorities; two national non-governmental organisations; two private sector care providers; a community group; and two social enterprises. Between them, participants included both commissioners and providers of services designed to support the well-being of people living with dementia.

Discussion groups and interviews were structured around the theme of 'living well with dementia'. A list of important constituents of a good life with dementia was presented to participants as a discussion point. This list was developed by the Alzheimer's Society (AS 2010) through in-depth research with people living with dementia; participants therefore viewed it as a meaningful and

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legitimate starting point for open discussion. Using this list as a prompting device also ensured that the voices of people with dementia provided the foundation of the discussions. The central domains valued by those living with dementia were: 'Relationships or someone to talk to'; 'Environment'; 'Physical health'; 'Sense of humour'; 'Independence'; 'Ability to communicate'; 'Sense of personal identity'; 'Ability or opportunity to engage in activities'; 'Ability to practise faith or religion'; and 'Experience of stigma.' Discussions were audio-recorded, transcribed, and analysed using thematic analysis. The analytical framework was Nussbaum's theoretical set of central capabilities (see above). Using the Alzheimer's Society list as research instrument, and Nussbaum's Central Capabilities as analytical framework, means that the final analysis combines empirical legitimacy with philosophical sophistication.

The following sections present findings for a subset of capabilities that emerged as especially important: 'Affiliation', 'Life', 'Bodily Health', 'Senses, Imaginations and Thought', 'Control over one's Environment' and 'Emotions'. It is notable that all of these, with the exception of Emotions, were identified as among the most important functionings on Nussbaum's list in a 'public reflective equilibrium' exercise with members of the public in the UK and Israel (Wolff and de-Shalit 2007). During the fieldwork reported here, 'Emotions' emerged as an additional priority domain, reflecting the heightened importance of subjective experience for people with dementia (see below).

Affiliation

There are two components of the capability for Affiliation: The first relates to social relationships in general, while the second, the 'social bases of self-respect', refers to recognition by society of each person's human dignity. Affiliation is defined as a central capability in its own right, and also as an organizing principle, since it "organize[s] and suffuse[s]" the other capabilities: social relationships have both intrinsic and instrumental value in a good human life (Nussbaum 2000:82).

The intrinsic value of affiliation

As discussed above, the capabilities account of well-being is grounded in an Aristotelian social-relational account of personhood and the good life. On this account, Affiliation would be expected to form a necessary constituent of living well with dementia. In support of its conceptual importance, discussion participants did indeed identify Affiliation as a central part of living well with dementia:

> "I think that relationships and social connections is the one that probably stands out for me, I just think that it's got a lot of different levels…that feeling of remaining connected to other people." (2:Private Sector)[iii]

> "It's like people who live on their own and they go and stay with their families for a week or two, and the families say, 'Gosh, by the end of the holiday it was like they were back to normal'. So I think it's just having that constant social stimulation." (1:Social Enterprise)

It was even suggested that the capability for affiliation is sufficient for personhood:

> "I feel personally that there is something [of a person] that will always remain… I've come to that conclusion based on how people do still remain responsive to interactions with other people. Even if it's really limited, there's always going to be something there." (2:NGO)

This suggests that affiliation in some form is often possible even when other capabilities are severely diminished. This implies that, even in advanced dementia, personhood (on an Aristotelian account) remains intact, and so the life of that person continues to be a life worthy of respect.

Both close personal relationships and the looser ties of wider social affiliation are important aspects of Affiliation. Close relationships with families and friends, and especially with family carers, constitute a central part of living well with dementia. Participants often used a social definition of well-being, focusing on inter-dependence and the shared ends and joint challenges of people with dementia and their families.

> "I think anybody with dementia, you know, it's a completely interdependent scenario with their carer, I don't think you can ever get away from the fact that, particularly if you've got a carer who's a partner, they're particularly integrated in that person's life. Carers need as much support as the person with dementia does…in terms of policy decisions, I think we often don't appreciate that we can't just look at the person with dementia."
> (2:Public Service Commissioner)

This quote demonstrates that people with dementia and family carers have both specific individual needs, and many shared ends relating to the capability to live well together. However, dementia can cause great strain on close relationships. This evidence These findings emphasises the need to understand a person with dementia in the context of their social network, and highlights the vital role of support for this wider network – for family carers, and families and friends in general.

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A social model of dementia extends beyond close personal relationships to include the looser ties of wider social affiliation. At the most general level, social attitudes play a central role in people's ability to live well with dementia, and the social bases of self-respect. The stigma surrounding dementia often stems from fear and misunderstanding:

> "There is a real lack of understanding and compassion actually for people with memory problems. It's like cancer was a long time ago, you know, nobody spoke about it." (2:Public Service Commissioner)

An important theme to emerge in relation to this was the importance of recognition, patience and understanding on the part of service workers, such as people working in shops and public transport:

> "Getting on a bus can be very worrying and frightening: where to get off, have I got enough money, will the driver be patient?" (Telephone:NGO)

> "[At the supermarket checkout] there was a lady, she obviously couldn't open her purse, and in the end the young woman at the till took the purse from her…I said to her, 'Oh, you were marvellous', and she said, 'Well that lady comes to me especially,' so she knew her." (2:Community Worker)

These examples highlight the importance of awareness among service workers in enabling people with dementia to access services and amenities.

As well as service workers, the general public also have an important role in creating 'dementia-friendly communities' (AS 2013) that can promote secure functionings for people living with dementia:

> "… she could end up not knowing where she is, but if you could feel confident that, you know, the bus driver's going to be kind, if people around her in the shop or wherever will know her and know where to send her back to, everything changes. Instead of it feeling like a world full of dangerous strangers, if it felt like a world full of people who would help, it changes her world." (2:NGO)

This quote expresses the transformational potential of a dementia-friendly social environment for a person's capability to live well as part of a community and to access the public spaces and institutions of everyday life. It also highlights the close connection between social interaction and the social bases of self-respect. Supporting social inclusion and involvement in everyday activities expresses respect for people's basic human dignity, by not defining them solely by their impairment. This avoids stigma – both self-stigma and stigma from others – and is a central element of the social bases of self-respect.

Inter-personal communication is, by definition, a central aspect of affiliation; however, dementia can erode speech and language.

> "It becomes more than, I guess, communication in a traditional sense, it's not about having a conversation like this and saying 'I would like this, I would like that' – that decision-making and agency." (2:Public Service Commissioner)

It is striking that this participant disassociates social interaction from an idealized rationality, suggesting that meaningful communication and affiliation are not necessarily dependent on the ability to engage in "traditional" cognitive and semantic reasoning.

The instrumental value of affiliation

The empirical findings showed that, as well as its intrinsic value, social interaction buttresses many other functionings, and a break-down of affiliation is likely to create vulnerability in terms of secure functionings:

> "People [often] lose their friends after diagnosis, and you hear those stories about what a massive impact that has on people in so many different ways." (2:NGO)

Affiliation is instrumentally valuable in a plurality of functioning domains. In a discussion about a social programme for people with dementia, a participant observed:

> "… enabling people to communicate and express themselves means they don't feel the same levels of distress, and we've found amazing clinical outcomes as well as social outcomes, in people's memory tests and other tests that have been done by clinicians…"
> (2:Public Service Commissioner)

The role played by Affiliation in supporting secure functioning in emotional and cognitive health suggests that it may be a 'fertile functioning.' In support of this, the instrumental role of Affiliation in other central functioning domains is set out below.

Life and Bodily Health

Despite the many challenges faced by people with dementia, participants agreed that a life worth living with dementia is certainly possible. At the level of social institutions, access to suitable health and social care is clearly foundational to the capabilities for life and bodily health for people with dementia, as it is for all older people and all people in general. Because people with dementia (especially at the advanced stages) may be less able to take care of themselves, the enabling role of others takes on increased importance in the domains of life and bodily health. Awareness among health workers is crucial:

> "In hospital, making sure the staff are aware that the person has dementia and they won't remember their glass of water, you've got to sit with them." (2:NGO)

The active awareness of medical workers of the vulnerabilities of people with different types and at different stages of dementia is an important social feature of secure functioning in the area of health, especially since people with dementia may have diminished ability to communicate and self-advocate.

Affiliation can also support people with dementia to engage in physical activity:

> "There's one activity called Circle Dancing for Dementia, and it's especially good in care homes…as soon as the music starts people start moving…so they get some exercise, but the word 'exercise' is banned because that puts everybody off!" (1:Private Sector)

This example showcases a sensitive approach to supporting the bodily health of people with dementia. The activity is founded on Affiliation: it is facilitated by others and performed together as a group; and the social bases of self-respect are reinforced through consideration of the social barriers that might prevent people from participating.

Emotions

Affiliation is also foundational in the domain of Emotions. Participants discussed many elements of emotional well-being, including feelings of happiness; being able to show love and give care; and humour.

Some models of dementia-care prioritise subjective well-being, for instance, the 'Contented Dementia' approach advocated by James (2008). These approaches, like hedonic accounts of well-being in general, can be criticised for their value-monism, and for over-valuing subjective states ('happiness' or 'contentment'), to the detriment of other aspects of a flourishing life (Austin 2016). However, participants suggested that subjective contentment may be particularly important to people with dementia, given the anxiety, fear and depression that can accompany the disease:

> "The people I see, I see many of them that are just sad, and I suppose I'd rather they were anything other than sad." (1:NGO)

The special importance of subjective well-being is also linked to the observation that people with dementia, particularly those at a more advanced stage, have impaired access to memory and to the ability to plan ahead, so their immediate mind-state is especially important:

> "People, especially people with advanced dementia, are living in the moment, so feeling content is more important for them." (Telephone:NGO)

This suggests that subjective well-being may take on increasing significance as other capabilities become diminished. However, most participants suggested that, important though it is, subjective well-being must be balanced against other considerations: an appearance of placid contentment cannot be taken as a sign that a person is living well with dementia, since it could indicate that she is under-stimulated or over-medicated. Again, the social-relational foundation of subjective well-being is central:

> "I'm thinking of a gentleman I saw last week who can't even hold a conversation anymore, but anything we can do to make him feel, in the moment, content, and listened to and valued, is going to be a big improvement on his current situation." (1:Community Worker)

Another important relational aspect of Emotions is the need to recognise people with dementia not only as recipients of care, but having the capacity and need to give care.

> "There's one lady that we visit and give some companionship to, and the pretence is that we're just popping round and she's helping us, and that helps her to feel, you know, she acts as the perfect hostess, she offers tea, and we might have to help her make it, but she's offering it because it makes her feel - she was a very sociable lady, and she did help a lot of people in her community when she was younger." (1:Community Worker)

This example highlights the importance of the opportunity to give care in supporting people's capability to feel emotions such as happiness, belonging and respect - both the respect of others and self-respect.

A final aspect of emotional well-being is humour.

> "…whoever it was who was giving her fish and chips was talking about Blackpool [seaside town] and having a laugh and a joke, and 'Oh I've been to Blackpool for these fish and chips!'" (1:Social Enterprise)

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The importance of humour lies in the social and relational aspects of sharing a laugh and a joke, as well as the role of humour in creating a sense of normality, and connecting with a person on a distinctly human level.

Overall, the discussions suggested that emotional well-being is relational, and Affiliation is a necessary condition for secure functioning in this domain.

Senses, Imagination and Thought

Strategies for engaging the senses and imaginations of people with dementia, such as art and music therapies, are relatively common in dementia care, and these experiences can enhance well-being in a number of different ways.

> "They might have no recognition whatever, but experiencing something kind of takes you to a place. You may not have the words, but the smells, you recognise it…It's about what art can trigger…if you explore a painting together, it's how you respond to that painting…We did some work recently with a day centre and nursing home, and the conversations that people had, through sounds, objects, we've got a box of objects that got people talking." (2:Art Therapist)

Experiences involving senses, imagination and thought, particularly relating to art and music, may be important because of the immediate experiential pleasure they can provide. As the quote above suggests, this kind of experience need not always require high levels of semantic or cognitive ('rational') engagement beyond the direct sensory experience. Moreover, this kind of experience is likely to be dependent on social interaction of some form; affiliation, again, is of instrumental value for secure functioning in the sphere of Senses, Imagination and Thought.

Control over one's environment

Control over one's environment encompasses (A) the political environment and (B) the material environment.

(A) Control over the political environment

Considering first control over the political environment, there are two main aspects for people with dementia: first, participation in the political life of the wider community and the nation; and second, participation in decision-making relating to a person's immediate environment and to their care.

With regard to participation in electoral politics at the local and national levels, different people have different levels of capacity and interest, depending on a variety of factors, including, for

example, the type and stage of dementia, and their personal interest in politics. Nussbaum (2007) suggests that guardianship arrangements can be a useful means of enabling people with impaired cognitive capacity to participate in this type of activity. This demonstrates the role of affiliation in the creation of capability and secure functioning in this domain.

The second aspect of control over the political environment is participation in decisions that affect everyday life. Given that people with dementia have greater dependence on others for secure functioning in many domains, it seems especially important that there should be mechanisms to enable involvement in decision-making. This might range from including people in choices about what to wear each day, to advance care directives that enable people to have deeper and more general involvement in how they wish to be cared for at later stages. It may also be possible for some people with dementia to be involved in the evaluation of services (Cheston et al 2000).

(B) Control over the material environment

For people with dementia, the capability for control over the material environment may refer to the relatively limited environment of a residential care home, or to private homes and the wider community. For people living in the community, the capability for control over the material environment depends on a great number of actors and agencies, including every-day institutions (including the people who work in them), the wider public, and the physical (built) environment.

The priority of making public spaces easy to navigate and use, for example through clear signage and places to sit down, was highlighted as an important enabler of control over the environment:

> "[We need] universal public spaces to be welcoming, you know, the physical environment or the building to be designed in a way which means that somebody with dementia could get around: It's not confusing, there aren't too many falls risks, you know, all the walls don't look the same so you don't know which corridor you're in." (2:Public Service Commissioner)

The role of affiliation – of both close others and the wider social group - in enabling people with dementia to have control over their political and material environment is clear. On the other hand, participants noted that conflicts can arise between the interests of a person with dementia and family members and carers. There are inevitable imbalances of power involved in these relationships, and exploitation, including financial exploitation, cannot be discounted (e.g. Pinsker et al 2010). This suggests that affiliation is necessary but not sufficient for secure control over one's political and

material environment, since other features of the material and policy environment play an important role.

Discussion and Conclusion

This paper has situated 'Living well with dementia' as an issue of social justice. Some theories of justice do better than others in relation to disability in general, and dementia in particular. While classical social contract theories rely on narrow assumptions about mutual advantage and individual rational agency, alternative approaches are able to accommodate people with impairments as primary subjects of justice, due to different assumptions about the nature of personhood and well-being.

The Disadvantage and Capabilities approaches demonstrate how the classical assumptions can be replaced with a social account of personhood and well-being as relational (not individual) concepts. This social account is based on recognition of the bonds of solidarity, dependence and care that constitute a human life. The empirical part of the paper provides support for the modification of the classical contractarian assumptions, in favour of a focus on shared ends, patiency, and an account of personhood that does not rely on a narrow, idealized account of rationality.

The Disadvantage approach pioneered by Wolff and de-Shalit provides a theoretical framework for (1) identifying vulnerable groups based on the presence of clustered disadvantage and (2) developing strategies for reducing vulnerability and enhancing well-being among the disadvantaged, through the identification of fertile functionings. First, the international evidence shows that people living with dementia suffer clustered disadvantage - insecure functioning across multiple domains of life. Improving the lives of this vulnerable group is therefore an urgent issue of justice. Second, this study has highlighted the intrinsic and instrumental value of affiliation in the creation of social arrangements that enable people to live well with dementia.

It is notable that the empirical finding of affiliation as a fertile functioning aligns with Nussbaum's identification (based on philosophical reasoning) of affiliation as playing a special role in a good human life, organizing and suffusing other capabilities (2000:82). Another particularly noteworthy conclusion emerging from the empirical findings is that, in contrast to the Kantian position that individual rational agency is the foundation of personhood, an Aristotelian account of the capability for affiliation as the basis of personhood enables the inclusion of persons with cognitive impairments as primary subjects of justice.

In practical terms, supporting the social relationships of people with dementia sustains and promotes secure functioning in multiple domains, and enables people to live well with dementia together. As well as close personal relationships, the weak ties of affiliation - for example, patient and understanding service workers, and passers-by who are willing to help - enable a person with dementia to participate in the life of her community, and are part of the social bases of self-respect. In summary, this paper has suggested that affiliation - the strong and weak ties of social life – is a fertile functioning, a multiplier of advantage that underpins and catalyses secure functioning across a plurality of domains. It follows that, when resources are limited and pragmatic decisions must be made between multiple valuable ends, a focus on affiliation would be a reasonable policy strategy.

In relation to resources, research participants emphasised that a focus on affiliation would not necessarily lead to increased expenditure, and could actually save money. For example, during discussions around simple and creative ways to improve the quality of everyday interactions between people living with dementia and paid carers, participants observed:

> "Actually that doesn't cost any more money whatsoever… there isn't any more money in the system, so you can't expect to start commissioning vastly expensive specialist services, but actually [in any case] the traditional models of care are not fit for purpose for people with dementia." (2: Public Service Commissioner)

> "Spending an hour with somebody rather than fifteen minutes… all of those simple things … I believe it would save money overall." (2: Community Worker)

This is a further indication, from the perspectives of professionals involved in budgeting for dementia care, that supporting secure affiliation would be both a reasonable and desirable strategy for public policy to address dementia-related social injustice.

Conclusion

Justice requires that public policy improve the lives of the disadvantaged. Dementia is a source of multiple disadvantages. Therefore, as a matter of social justice, public policy should aim to improve the well-being of people living with dementia. Non-contractarian approaches to justice, such as the Capabilities Approach, are better equipped than their contractarian counterparts to conceptualise and analyse issues of justice and disability, and therefore to provide a sound foundation for ethical public health policy. Through an analysis of original empirical research, this study shows that, in the

Article accepted for publication 1/11/16
Public Health Ethics, DOI: 10.1093/phe/phw045

context of dementia, affiliation is a 'fertile functioning': as well as its intrinsic value in living well with dementia, it is instrumental in many other valuable functionings. This confers a duty on society to strive to achieve secure affiliation for all people living with dementia, as the foundation of a just society in which a life with dementia is valued as a dignified and worthwhile human life.

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Notes

[i]Reader (2007) defines 'patiency' as the obverse of 'agency'.

[ii]Cognitive impairment poses an especially complex set of ethical questions in relation to practical reasoning, agency and personal identity (e.g. Dworkin 1993). These are set aside in the current paper. See Chiong (2012) for an overview.

[iii]Quotation references show group number and organisation or role of participant. For example, '2:NGO' means that the cited participant was in Group 2, and worked for a non-governmental organisation.

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Article accepted for publication 1/11/16
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