Article

Rights in mind: Thinking

differently about dementia

and disability

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Abstract

The aim of this paper is to argue for the utility of a relational model of disability, as a way of

conceptualizing dementia. We explore whether dementia should be considered as a disability, and

whether people with dementia might consider themselves as disabled people. We review

examples of, and issues raised by, the political activism of people with dementia. We consider

how language constructs dementia negatively. We discuss how the environment influences the

experience of dementia. In conclusion, we show that a relational model of dementia lays the basis

for a human rights approach to the condition, based on collaborative partnerships between

people with dementia and people from other disability communities.

Keywords

human rights, models of disability, environmental barriers, activism

Introduction

Dementia and disability seem like planets spinning on different axes, their inhabitants aware

of each other’s existence but apparently unable to communicate (Mittler, 2016a). There is a

perception in the disability world that dementia is solely a health responsibility. People with

dementia do not necessarily think of themselves as disabled. But the planets are aligning.

Dementia Alliance International – all of whose members have a medical diagnosis –

demanded access to the Convention on the Rights of Persons with Disabilities (CRPD) at

the World Health Organization’s (WHO’s) First Ministerial Conference on Dementia

 (WHO, 2015). A strong human-rights-based resolution proposed by Alzheimer’s Disease

International was unanimously approved and later incorporated into the Concluding Call

for Action by WHO Director General, Dr Margaret Chan.

Work is now in progress to make a reality of that demand (Dementia Alliance

International, 2016). Several recent interventions have proposed adopting a social model

approach to dementia, borrowing from innovations in disability studies (Thomas &

Milligan, 2015; Mental Health Foundation (MHF), 2015). A social model approach

distinguishes between the illness/impairment, and the oppression or exclusion that people

with the illness/impairment experience. A social model would focus on the social barriers

faced by people with illnesses and impairments. However, this classic social model approach

does not fully account for the complexity of the disability experience (Shakespeare, 2006),

and so we will argue that it cannot do the required job in terms of dementia. Our suggestion

in this paper is that a more innovative approach to dementia is required. This approach must

give appropriate weight both to the condition itself, and to the social relations within which

people with the condition, and their families, live. Dementia, like disability in general, is a

multi-dimensional phenomenon, and requires a response that addresses different aspects,

including clinical, psychological, social and political.

We suggest that regarding dementia as a disability could be beneficial for people living

with dementia. As noted by Angus and Bowen-Osborne (2014):

‘Disability and illness narratives can provide us with the opportunity to circumvent a reliance on

a description of the physical impairment and expose attitudes and practices imposed upon a

person. . .’

We are also interested in whether categorizing dementia as a disability may help us to

explore some of the ways that barriers and discourses shape experiences of the condition.

Perhaps most importantly, we hypothesize that seeing dementia as a disability could place

people with dementia, as self-advocates, at the centre of their own stories, and help provide

an enabling identity.

Dementia as disability

We need to start by asking whether or not dementia is a disability (or impairment, to use

social model language, see Oliver, 1990). This is different from the question of whether

people with dementia consider themselves disabled. The first question can be answered

more or less objectively, the second question is subjective, depending on the attitudes,

values and experiences of individual people with dementia themselves.

The WHO International Classification of Functioning, Disability and Health (ICF)

defines disability as ‘an umbrella term for impairments, activity limitations and

participation restrictions’ (WHO, 2002, p. 2), referring to the negative aspects of the

interaction between an individual with a health condition and that individual’s contextual

factors (environmental and personal factors):

According to Article 1 of the UN CRPD:

‘Persons with disabilities include those who have long-term physical, mental, intellectual or

sensory impairments which in interaction with various barriers may hinder their full and

effective participation in society on an equal basis with others.’

In UK law, the Equality Act 2010 states that a person (P) has a disability if:

(a) P has a physical or mental impairment, and

(b) the impairment has a substantial and long-term adverse effect on P’s ability to carry out

normal day-to-day activities.

In general terms, the dementia syndrome is characterized by progressive decline in cognition

of sufficient severity to interfere with activities of daily living (Knopman et al., 2001).

Therefore, dementia may be seen as having the features of a disability, in the same way as

other degenerative conditions such as Huntington’s disease, multiple sclerosis or Parkinson’s

disease. The fact that a specific disease or syndrome – such as Alzheimer’s – is hard to

diagnose and define does not negate this. Other health conditions, such as schizophrenia

or autism, are equally complex, and yet it is clear to most observers that they can be usefully

regarded as disabilities because they are associated with difficulties in functioning.

Epidemiologists generally categorise dementia among the wider category of disabilities

(Alzheimers Disease International and World Health Organisation (ADI and WHO),

2012, p. 8; Stephan & Brayne, 2010, p. 14; WHO, 2003). So we would argue that from

semantic, epidemiological and legal perspectives, dementia is a disability.

The answer to the second question, concerning whether people with dementia think of

themselves as disabled, will always be provisional. As with the co-author of this paper, some

people living with early-stage dementia have strongly articulated a disability identification;

some are reluctant to do so; others are silent (Whitman, 2015). Many will reject what they

may perceive as another stigmatising label.

However, this is not very different from people with other impairments. A study carried

out for the Department for Work and Pensions found that 52% of people with rights under

the Disability Discrimination Act did not identify as disabled (Department for Work and

Pensions (DWP), 2002). Many people with learning difficulties are reluctant to adopt the

label disabled, as are many Deaf people (Shakespeare, 2006). Older people, who make up

around half of all disabled people, can view their functional deficits as part of normal ageing,

and hence are less likely to identify as disabled (Kelley-Moore, Schumacher, Kahana, &

Kahana, 2006). We can anticipate that people with dementia will also vary in their

willingness to identify as disabled. But like other groups, they can still use the UN CRPD

as a tool to advance their rights.

Certainly, people with dementia are not seen by the general public, professionals or by

other disabled people as part of the disability rights community. The dementia community

has never been part of the disability movement, and did not join forces with the powerful

coalition of disabled people’s organisations which campaigned for the Convention (Sabatello

& Schulze, 2014). This is the paradox that we are seeking to address in this paper.

Dementia is a decrement in functioning (WHO, 2002), but the corollary that people with

dementia are disabled is harder to accept. If people with dementia are a specific group, then

they have rights and an ability to articulate their own needs (Swaffer, 2016; Taylor, 2007).

This was clearly articulated by Marshall some 16 years ago (as noted by Gilliard, Means,

Beattie, & Daker-White, 2005, p. 576) arguing for the positive benefits of regarding dementia

as a disability. We recognise the danger of subsuming all people with dementia (who are

innately diverse and who are affected differently) into one group, let alone into the wider

disability community. But forming a unitary movement was no less challenging for people

with mental health conditions (Wallcraft & Bryant, 2003).

More than a medical condition

The banner under which other disability communities have united is opposition to

inappropriate medicalisation. The point about the social model of disability is that it

distinguishes between the health condition, on the one foot, and the social experience of

exclusion, on the other. However, dementia still remains trapped within the dominant

medical discourse.

Since the late 1990s, there has been a slow but steady movement away from the tendency

to view dementia solely within a medical framework (Ballenger, 2006; Basting, 2009; Killick,

2013; Kitwood, 1997; Sabat, 2014). Kitwood’s notion (1990) of ‘malignant social

psychology’ was perhaps the seminal conceptualization provoking a reconsideration of the

role of social environment for people with dementia. Reliance on a solely medical framework

has been increasingly criticised for maintaining the exclusion and passive dependency of

people with dementia: ‘It is important. . .. to identify correctly what constitutes a symptom

of neuropathology as opposed to an appropriate emotional reaction to an extremely

undesirable situation or to dysfunctional social treatment’ (Sabat, 2008, p. 71). In both

research and policy, an increased understanding of the ways in which social dimensions

can be influential (positively and negatively) has helped re-focus dementia research on the

person, rather than solely the illness. (Gilliard et al., 2005).

Practice has been slower to change. In 2015, the Organisation for Economic Co-operation

and Development (OECD) stated that dementia receives ‘the worst quality of care in the

developed world’ (2015). But there is an increasing focus on improving quality of life for

people with dementia (Gross, Danilova, Vandehey, & Diekhoff, 2015), including the social

conditions in which people live, whether in care homes or in the community (Dodd & Bush,

2013). The importance of investigating ‘nonpharmacologic tools’ has also been widely

embraced across the US (Kaldy, 2013).

Pioneering work by researchers and practitioners has contributed to the understanding

that although Alzheimer’s and other dementias may be incurable at present, they are

conditions that can be treated. While antipsychotics may work for some people, treatment

always includes more than drugs and requires attention to the social environment in which

people with dementia live (Killick, 2013; Kitwood, 1997; Sabat, 2001; Zeisel, 2009). WHO

promotes a model of Healthy Ageing, which takes the environment into account, not just

intrinsic capacity (WHO, 2016).

Nevertheless, medicalisation still predominates. This is partly a product of biomedical

models of illness that can be traced back to the Enlightenment (Bond, 2001). One

consequence of the medicalisation of dementia is the way in which disease is seen as the

loss of ‘normality’ with the associated labelling of people with dementia as ‘victims’ or

‘sufferers’ (Bond, 2001, p. 45). An important influence is the financial dominance of

pharmaceutical companies, which are primarily concerned with the huge market in drugs

for these conditions (Moynihan & Cassels, 2006). The tendency to over-medicalise dementia,

and people with dementia, has obscured the importance of social conditions that contribute

to disabling people with the condition.

People with dementia are activists too

One factor that may account for the continued over-medicalisation is the relatively recent

emergence of dementia activism. Political action by people with mental health

problems, physical impairments and those affected by HIV/AIDS (Campbell & Oliver,

1996; Hughes, 2009; Wallcraft & Bryant, 2003) has redefined these issues. Unlike the

disability movement, whose sustained advocacy led to the UN Convention (Mittler,

2016b), those with dementia have only recently started to unite and attempt to influence

policy. As noted by Bartlett:

‘Dementia activism is a newly emergent phenomenon. . . With few exceptions, activism by people

with dementia has not been the prime focus of research.’ (Bartlett 2014a, p. 624)

The novelty of dementia activism reflects the assumption that the rapid progression of the

illness means that individuals do not have the capacity to make speeches or campaign. The

trend for earlier diagnoses, and the work of groups such as the Scottish Dementia Working

Group and the Dementia Engagement and Empowerment Project (DEEP, 2016) have

demonstrated how those with dementia can effectively unite and advocate.

At the international level, Dementia Alliance International (www.infodai.org) has led the

campaign for access to CRPD. For example, it has recently succeeded in persuading

Alzheimer’s Disease International to adopt a human-rights-based policy which includes

making full use of the UN CRPD and has submitted its own report to a UN General

Day of Discussion on Independent Living and Participation in the Community (Mittler,

2016c). DAI has facilitated exchange and discussion among people with dementia. For

example, a persistent theme raised in DAI writings and blogs is the ‘prescribed

disengagement’ (Swaffer, 2016) that accompanies diagnosis, with advice to stop work,

hand in their driving license and prepare for an early death. Another is the social

isolation that follows disclosure of diagnosis when friends, neighbours and family

members deliberately avoid meeting them (Taylor, 2007).

The human rights based approach (HRBA) is based on participation of people with lived

experience, as with the disability rights movement’s motto ‘nothing about us without us’. Yet

there is a shocking lack of consultation with people with dementia throughout much of

dementia care (Gilliard et al., 2005).

Self-advocacy is not straightforward in the case of dementia. Only those with mild to

moderate impairment are able to advocate for themselves or their peers, even with support

(Karlsson, SaÅN venstedt, Axelsson, & Zingmark, 2014). In addition, dementia activism can be

exhausting (Bartlett, 2014b). The short lifespan of the publication ‘The Voices of Dementia’,

a US journal of and by individuals living with the symptoms of dementia, shows that

continuity can be precarious.

Terry Pratchett is a pertinent example of one well-known UK dementia activist. He was

articulate about the effects of dementia, vociferous about the need for further funding and

better understanding about living well with the ‘embuggeration’ that is dementia:

‘I regarded finding I had a form of Alzheimer’s as an insult, and I decided to do my best to

marshal any kind of forces that I could against this wretched disease.’ (Pratchett, 2015)

Yet Pratchett was only able to be an activist for eight years. Nevertheless, Pratchett lived

longer with dementia than average. The brief life-span of those with dementia (it has been

estimated that on average men live for 4.1 years and women live for 4.6 years following onset

of dementia (Xie, Brayne, & Matthews, 2008)), makes it difficult for long-term change to be

achieved. As Bartlett (2014a) has convincingly outlined, ‘temporality’ is a distinctive feature

of dementia activism. This is partly because of the degenerative nature of the illness, but also

because the temporal structure of the condition is so perplexing. Campaigning within more

established disability rights networks may help dementia activism have a sustained impact.

Echoing the movement of people with learning difficulties, where supporters and advocates

add weight to the voice of lived experience, is another approach (Roberts, Turner, Baines, &

Hatton, 2012).

Towards a relational model of dementia

Interest in the social conditions that affect dementia reflects the burgeoning of communitybased

initiatives for people living with dementia. There has been a general movement away

from formal spaces designated for care and support toward a more diffuse range of

community-based spaces that are both accessible to and supportive of people with

dementia. In this context the policy-driven notion of Dementia Friendly Communities

(Department of Health, 2012) and campaigns such as ‘Dementia Friends’ might be

understood as reflecting this effort to re-think both the place of care and the ascription of

responsibility to provide care and support. So far, social responses to dementia have centred

on the need for awareness. In some ways, this echoes the early stages of disability politics. Yet

‘awareness’ and ‘friends’ are rather weak concepts.We argue that what is required is a stronger

response, an equalities-based approach, that recognizes that people with dementia are a

minority group in society, who are poorly served in many environments, and who

consequently face exclusion, even oppression. In several recent papers (MHF, 2015;

Thomas & Milligan, 2015), attempts have been made to outline a social model of dementia.

There is much sense in these papers, and they are to be welcomed. They are genuinely

committed to fresh thinking about the experience and response to dementia, and to the

empowerment of people who live with this condition. However, at the same time, we

believe they miss opportunities to outline how a social relational approach can be applied

to dementia, because their understanding of disability remains crude.

The original Union of Physically Impaired Against Segregation (UPIAS) (1976) model of

disability, labelled the social model and elaborated by Michael Oliver (1990), distinguishes

between impairment (medical) and disability (social), and focuses on social barriers and

oppression. It has been criticized for reducing the complexity of disability to crude

environmental determinism, and for ignoring the personal experiences of those living with

illness and impairment (Morris, 1991; Shakespeare, 2006). Because the social model was

developed to account for the experience of people with static physical impairments, it fails

adequately to contextualise impairments which are associated with pain; with limitation;

with frailty; and with degeneration. Despite the best efforts of Carol Thomas (1999, 2007),

the social model approach has also failed to make adequate space for psychological issues.

Dementia highlights again how the social model has never been very good at conceptualizing

cognitive impairments (Chappell, 1998) or mental health conditions (Beresford, 2012).

How do attitudes, environments and policies make life harder for people with dementia

(and their families)? How can inclusion be achieved? The MHF paper states this social model

aim clearly:

‘A social model approach argues that people with dementia must be viewed as a legitimate part

of mainstream society, living in communities as equal citizens with their value recognized and

respected.’ (MHF, 2015, p. 21)

However, it does not fully engage with the implications of this position. ‘Dementia Friendly

Communities’ are not enough. People with dementia have lived independently and been fully

participating members of their community all their lives but encounter deep-rooted and

systemic attitudinal and societal obstacles to continuing to do so following diagnosis. Even a

phrase like ‘dementia friendly’, while apparently positive, could be considered patronizing

and inappropriate. The implication is that the solution to the dementia problem is for people

without dementia to be kind and welcoming of people with dementia. But if the problem

includes socially imposed barriers, devaluing and even human rights violations, then the

term ‘friendly’ might be judged an inappropriate response, which we would not use for other

excluded groups. As Kate Swaffer has said, we might ask instead for ‘Dementia Enabling

Communities’. Long-term disability activist Ian Popperwell writes in his blog:

‘Subtle courtesies and acts of kindness can make all the difference to how any of us experience

our worlds, but for me there is an ugly flavour of charitable patronage when the term

‘friendliness’ is used instead of the carefully tried and tested words that speak much more of

rights, dignity, consistency and thoughtfulness.’ (Popperwell, 2014)

A more inclusive social model approach would ask: do mainstream services (health,

transport, housing) place barriers in the way of people with dementia? Do people receive

equal treatment? Is there ‘reasonable adjustment’ to the needs of people with dementia? For

example, people with dementia do not have their non-dementia health needs adequately

dealt with by the health service (see Alzheimer’s Society, 2016 report ‘Fix Dementia

Care’). This has also been found to be the case for people with learning disabilities and

people with mental health conditions (e.g. Melville et al., 2006). In response, doctors and

receptionists and others would need to change their ways of working to ensure that people

with dementia get screened for cancer, or get their flu immunization, or get referred for

investigations when they present with other symptoms, or get treated well in hospitals.

Moreover, a universal design philosophy, with an emphasis on barrier removal in physical

environments and also in information provision, would provide an overall context for the

many ongoing efforts to create more inclusive environments for people with dementia.

However, going further than universal design, it would be desirable to provide more

supportive responses to ensure that people with dementia feel welcome and included

(Nuffield Council on Bioethics, 2009). There is evidence that unsupportive environments

can contribute to anxiety and agitation for people with dementia (Chaudhury & Cooke,

2014, p. 144). One relevant initiative is the Personal Assistant – Dementia (PAD) role which

operates in Walsall. Individuals provide information, support and signposting to people in

the first three months after diagnosis. Due to marketisation, increasing consumer choice and

our growing reliance on online interactions, the world has arguably become more confusing

for everyone, and particularly for people with dementia as they seek to engage with services

in the public and private sector. For example, technologies like mobile phones and services

such as banking are very complex, demanding passwords and interactions that may exclude

or disable people with dementia (Batchelor, Bobrowicz, Mackenzie, & Milne, 2012; Nyga˚ rd

& Starkhammer, 2007). Yet technology could and should enable people with dementia

(Lauriks et al., 2007; Wherton & Monk, 2008). For example, in response to this socially

engendered disabling, the simple-to-use Raku phone has been developed in Japan. In the

classic case of mobility impairments, the disabling environment is very obvious (e.g. lack of

ramps and accessible bathrooms) and the solutions are clear. If an environment is rendered

accessible, and discrimination is effectively countered through education or legislation, then

people who use wheelchairs can participate on an equal basis with others. The solutions are

more complex for someone who lacks or is losing cognitive ability; whose fluctuating mental

health condition means that for days at a time, she/he is unable to get out of bed or interact

with others at work; or a person on the autistic spectrum who experiences neurodiversity.

Full equality for people with dementia may be elusive, but creatively inclusive responses are

long overdue.

A statement such as ‘The medical model maintains oppression, exclusive and passive

dependency of the person’ (MHF, 2015, p. 14) is a simplification of a very complex

process whereby a person with dementia ends up being treated as dependent and denied a

voice. Perhaps a better extrapolation of what happens when someone has dementia is that

she is viewed in terms of her inabilities, whether these are cognitive, relational or functional,

and in comparison to an expected norm of personhood. Her strength become invisible. Her

emotional and social bonds stand for nothing. Her disease and difficulties become her

defining features. On top of her diagnosis, a heavy weight of negative cultural

representation (Peel, 2014; Zeilig, 2014) clouds the collective vision of this person living

with dementia.

A relational disability model of dementia would take an adequate and nuanced approach

to dementia whereby there was both medical research into deficits and treatments, and

action to remove social, attitudinal and architectural barriers. Similarly, empowering

people with dementia as far as possible is clearly an important goal, but policy should

also recognize that people with dementia will require support and protection when their

disease makes it impossible for them to be active. The MHF paper refers to this approach

which ‘gives greater credence to the personal experience of having a disability, in conjunction

with the political and social contexts’ (2015, p. 15). This is seen as an appropriate approach,

given that ‘the majority of people with dementia frame dementia as an illness or disease’ and

that the ‘disabling factor may be intrinsic to the condition’. The author(s) conclude by saying

‘the social model needs to take account not only of the external barriers, but also of the

social and psychological obstacles that exclude or restrict full participation in society’ (p. 15).

This approach would look at how both the health condition itself, and the social

responses to it, generate the disability (Shakespeare, 2006). Such an approach could be

conceived in terms of the ICF (WHO, 2002), where disability arises from the interaction

of a health condition with environmental factors and personal factors. Alternatively, various

scholars have proposed a critical realist approach to disability (Danermark & Gellerstedt,

2004; Shakespeare, 2006), entailing a laminated model. This refers to the different levels – the

biological, the psychological, the environmental, the social, the legal – which interact to

produce the experience of disability. We believe this could offer a more adequate

understanding of the complexity of dementia.

Dementia as a human rights issue

The corollary of regarding dementia as a form of disability, and articulating either a social or

relational disability model of dementia, is that dementia should be regarded as a human

rights issue. At the domestic UK level, this means the Equality Act, and at the international

level the equivalent is the CRPD, which the UK ratified in 2009. As the MHF (2015), Neil

Crowther (2015), Peter Mittler (2016a, 2016b) and others have argued, it is long overdue for

the CRPD to be applied to, and used by, the dementia community. It is frequently said that

the CRPD uses a social model of disability. Article 1 talks about the interaction of

impairments with various barriers. Rather than a traditional social model, this would be

better interpreted as endorsing the relational approach discussed above. In other words,

both the impairment and the barriers, interacting together, hinder full and effective

participation in society.

The CRPD offers benefits to people diagnosed with dementia, in particular Article 12,

which states that people with disabilities have legal capacity on an equal basis with others.

Status-based approaches to capacity are discriminatory: rather than taking away someone’s

driving license when they are diagnosed, it should depend on independent assessment of

capacity to drive, i.e. a functional approach to capacity. Article 12 promotes supported,

rather than substitute, decision making, which could be a beneficial process in dementia.

Rather than automatic guardianship as soon as someone shows signs of cognitive

impairment, the principle of ‘supported decision making’ entails working with the

individual to ascertain their will and preference. Yet dementia also challenges Article 12.

The Essex Autonomy Project (2014) and many psychiatrists, philosophers and lawyers (e.g.

Dawson, 2015; Freeman et al., 2015) have found the wording and implications of Article 12

and its radical interpretations very hard to elucidate or implement practically. Nuffield

Council on Bioethics (2009) and others have stressed instead ‘joint decision-making’ with

trusted family or friends.

A second area in which dementia – and other complex conditions – challenges the CRPD

concerns the role of the family and other informal carers of people with dementia. Carers

also share the lived experience of dementia (Nuffield Council on Bioethics, 2009). Family

members are largely absent from the CRPD, aside from an explicit mention in the Preamble

and implicitly in Article 23, ‘Respect for home and family’. The absence of family members

or other third parties reminds us that a human rights approach is essentially individualistic.

An individual makes a claim because their rights are violated. Yet people live their lives

relationally. In every state, including the wealthiest, informal carers provide the majority of

assistance (WHO, 2011). To the extent that it fails to engage with the experiences of people

with dementia – or indeed profound intellectual disabilities – the CRPD promotes the liberal

individualist fiction, rather than the complex, messy, interdependent reality of life.

Conclusion

Bringing dementia within the disability rights mainstream is not easy. The usual language of

disability rights is hard to apply. What would ‘Dementia Pride’ mean, for example? There

may be no world in which it would be easy to have dementia (or Motor Neurone Disease or

Parkinson’s), but there should be a world in which it is possible to live better with these

conditions. Hence the emphasis on Living Well with Dementia (Swaffer, 2016) or Living

Beyond Dementia.

As with other areas of disability politics, there is a danger of a Pollyanna-ish approach,

which overlooks the unpleasant and difficult aspects of having an illness or impairment

(Carel 2008). That is why taking dementia seriously means reconfiguring our approaches

to disability as a whole. The condition of dementia challenges the disability community to

remember how impairments can impact daily living, and how emotionality is important.

It also reminds us how humans can communicate and connect without language, and that we

 Shakespeare et al. 9

are more than our memories (Banner, 2014; Basting, 2009). As noted by the activist Richard

Taylor:

‘It is true that I am fundamentally different from you. I am different in ways I can’t express and

you can’t fully perceive or understand. Our brains are different. But I am still a complete human

being.’ (Taylor, 2011)

Here Taylor asserts both his status as ‘different’ and also his fundamental completeness and

thus similarity to all human beings. Dementia highlights the diversity of disability. We often

speak as if there is one shared disability experience. We talk of disabled people, which

implies a unity. Yet there are many experiences. Impairments and illness differ in the way

they affect people, and the extent to which they affect people. There is a particular distinction

between impairments that are physical or sensory, and those that have a cognitive

dimension:

people with learning difficulties and people with mental illness are more excluded. We argue that

people with dementia are among the most excluded, by virtue of the loss of experience and

relationships which they have enjoyed throughout their lives.

The work of Hughes (2014), Killick (2013) and Sabat (2008) attests to the possibility that

people with dementia can maintain reciprocal relationships, even at fairly advanced stages of

the illness, and confirm the persistence of relationality. This sense of ‘being with others’ (a

concept borrowed from the philosopher Heidegger), the cultural and social exchange and

sharing that continues for people with dementia, is perhaps the strongest indication that

personhood and identity are not destroyed by dementia. If we are beginning to understand

the voice that people with dementia retain, and the possibilities for a more expanded

understanding of personhood, then we open the doors to a more powerful articulation of

the rights of people with dementia and thus their ability to retain their humanity to the end

of their lives.

We have argued here that it is vital to situate the individual experience of dementia in the

broader social context. We also need to articulate a human rights perspective in which selfadvocacy

is core. We need to expand our ideas about social models and about human rights

in order to incorporate the experience of all human beings, including people living with

dementia. We are embarking on a project of cultural transformation (Scully, 2012, p. 72).

Seeing dementia as a disability, within whatever version of the social or laminated model

you choose, might be very helpful for people with this condition. But it is unclear at the

moment how it could be operationalised. We lack sufficient consistent work inclusive of

people with dementia, and activism of people with dementia themselves over a period of

time. This paper has been a collaboration between a disabled person, a person with a mental

health condition, and a person living with dementia. Our combined experiences of living with

disability have added depth to our understanding, both at the level of lived experience and

intellectual endeavour. The politics of dementia demands that people with and without the

condition work together. Understanding the experience of dementia means incorporating the

psychological and the cultural and the structural with the medical. This is a complex

enterprise.

As a society, if we can assimilate and acknowledge all that dementia implies, and the

diverse ways in which people with dementia want to live, then we will also have a more

profound understanding of life, and all that it entails – not just decay, loss, transience and

difficulty, but also joy, love and friendship. The benefits will be felt not just by those living

with dementia, but by people living with disability – and indeed, everyone.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or

publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this

article.

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12  Dementia 0(0)

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14  Dementia 0(0)