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Lifelong Learning and Dementia: A Posthumanist Perspective

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Palgrave Pivot

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Chapter One

Abstract

In this chapter we introduce the key arguments of this book. First, a posthumanist perspective helps understand and value the lives of people with dementia and second, they are capable of learning and teaching. It introduces dementia as a global social issue and cultural phenomenon and critiques the dominant narratives of loss and punishment surrounding it. Drawing on interviews with families of people with dementia it acknowledges the pain they experience, but also introduces a hopeful posthumanist perspective on dementia. The chapter shows that although arts interventions have demonstrated their creative potential, people with dementia have been largely absent from lifelong learning literature and policy. Finally, it outlines the research studies that will be used in this book *Beyond Words* and *Making Bridges with Music*.

Challenging the loss narrative of dementia: “it is not, it is still, that person”

‘Be kind and patient, for I have lost the best of me’, so reads a poem on the walls of a care home that looks after residents with dementia. This trope of loss shapes the dominant response to those experiencing dementia. Here dementia is nothing but a deficit state with all that is valuable left behind in the past. This book draws on our research with people with dementia and their close networks to challenge this vision of loss and to develop a different way of understanding dementia, drawing on posthuman ideas. Dementia is uniquely challenging because it undermines the certainty of identity, destabilising any sense that we know who and what we are as

humans or can trust that knowledge as a bedrock of our existence. The virtue of posthuman ideas is that they can help to understand that we are all in a relationship with the world that is not dependent on fixed boundaries, voice, identity and rationality; that questions our limited view of what a 'human' is. In more clearly revealing these unfixed relationships with the world, people with dementia may be in the vanguard, potential leaders not losers. In this book we value them as they are and move beyond dementia as a deficit category. Rather than positioning dementia as an educational wasteland, we see them both as learners and teachers and dementia as an essential but neglected part of lifelong learning.

JQ: And do you think in any way she is teaching you things?

Yeah, I mean you have got to start looking at things from a completely different perspective, so it has definitely helped me in ways of looking...and seeing different possibilities. (Helen, support care worker, interview).

Dementia: 'scourge', 'plague' and punishment

Dementia is an umbrella term for a range of conditions such as Alzheimer's disease, vascular dementia or mixed dementia. It is a terminal consequence of brain degeneration and is characterised by memory loss or confusion in interpreting space and meaning, often with a gradual reduction in speech, and is often accompanied by depression, anxiety and isolation. As Ken, husband of one of our participants, says, it tends to be a gradual process of 'plateau, dip, plateau dip, plateau dip...it's surprising how far you go before you face the fact that there is a real issue here.' Dementia is not confined to the elderly; Allegranti (2013) for example has conducted research with young people who have early onset dementia and their families. Nevertheless, with an ageing population, dementia is most likely to set in in advanced old age, once people

have survived other life threats: so that one in six people over 80 in the UK now get dementia. It is one of the most challenging social issues of our time.

If we don't get a handle on it it's going to be disastrous, it is a disaster now, it's going to be a crisis ...because there are so many people, so, so, many people.

(Ken, interview)

The popular metaphors dementia conjures are ones of contagion, and devastation: 'the scourge of our age' (Boseley, 2019, p.53) or 'the plague of our time' (Gerrard, 2019). There is a strong sense of punishment in the way that dementia is framed. Dementia is punishment for living too long, punishment for the hubris of cherishing personal identity and freedom. In *Illness as Metaphor* (1978, p.1) Susan Sontag famously challenged such metaphorical thinking:

My subject is not physical illness itself but the uses of illness as a figure or metaphor. My point is that illness is *not* a metaphor, and that the most truthful way of regarding illness—and the healthiest way of being ill—is one most purified of, most resistant to, metaphoric thinking. Yet it is hardly possible to take up one's residence in the kingdom of the ill unprejudiced by the lurid metaphors with which it has been landscaped.

The punishment narrative of dementia has been naturalised, much like the metaphors attached to cancer and TB that Sontag discusses, and in order to rethink dementia we must abandon this landscape.

This is not easy to do. There are very few people who have not been touched by dementia. We can ourselves draw on past and present experience of supporting those with dementia within our close networks and this has not been comfortable or easy.

I watched as H gradually forgot many of the people who had been most important to her. I heard her panic and speak in a babble and leave the TV on a rolling programme of the shopping channel. Now J is also in a nursing home for her own safety. She still looks up into the blue and exclaims 'look at that sky!' (JQ diary)

There are some hopeful signs that the loss narrative is being contested. One of the objectives of the UK interdisciplinary programme *Created out of Mind* was to explore and contest assumptions about dementia through a range of measures including analysis of media discourse and opportunities to communicate with people with dementia via digital media. Zeilig, West and van der Byl Williams (2018) outline how this programme produced opportunities for 'co-creativity' which challenge the dominant biomedical and social paradigms that associate 'dementia' with irretrievable loss and decline. In a sociological context, Jenkins (2014) critiques the person-centred interventions that make up the current landscape of dementia care which, seek to 'revive or repair a hitherto 'broken' self' (Jenkins, 2014, p.7). Jenkins, on the other hand, demonstrates how people with dementia in Scotland have rejected the idea that they currently have no agency or selfhood and have formed their own campaigning groups where interacting with others can enable individuals to create a 'third self' beyond the self of the past or the self of dementia. As Kontos discusses, a diagnosis of Alzheimer's disease is habitually met with horror because it has connoted a loss of 'the self' and an entry into what has been termed 'social death'. Her own ethnographic research in a care home for people with Alzheimer's in Canada has led her to claim another form of selfhood for people with dementia: 'they interacted meaningfully with the world through activity and engagement rather than contemplation or reflection ... selfhood is embodied' (2004, p.831). She provides a rich picture of their embodied

lives and the pleasures and reciprocal moments therein, which includes dancing, singing, socialising and caring.

However, all these researchers still speak in terms of 'self', albeit a self that is differently constituted. As we shall discuss in Chapter Two, in this book we use posthuman ideas to move beyond notions of the self and see people with dementia in terms of 'agentic assemblages' (Bennett, 2010) and 'intra-activity' (Barad, 2007).

Dementia as a Global Issue and Cultural Phenomenon

The prevalence of dementia is a global health issue. Frightening statistics abound. According to the World Health Organisation in 2019 around 50 million people are living with dementia, with nearly 60% living in low and middle income countries. In 2019 the WHO estimated that by 2030 the total number of people with dementia will reach 82 million. According to the Alzheimer's Society it is now the predominant cause of death in England and Wales causing 12.8% of deaths in 2018. They estimate costs of dementia as more than cancer, stroke and heart attack combined (see Gerrard, 2019). At the same time there is an international crisis of social care for people with dementia.

In the UK dementia care is means tested, chaotic and punitive. Ken described the torturous process of applying for nursing funding for his wife:

Jane has the care appropriate to her needs that is her right... And that was a very trying and difficult and stressful process and I think of all the people particularly who are much older than me that may not be as pushy or as computer literate or could make a case, they get pushed aside, they are just, it's like a forgotten pile of need...The financial implications are enormous and it must

absolutely wreck lots and lots of people's lives financially and emotionally, the trauma of being a carer is bad enough without going through all that.

Dementia has also become a socio-cultural sensation with numerous newspaper articles featuring well-known people with dementia such as Terry Pratchett; best-selling books by dementia sufferers like *Somebody I Used to Know* by Wendy Mitchell (2018) or award winning accounts by campaigner such as Nicci Gerrard's *What Dementia Teaches us about Love* (2019). It provides substance and frameworks for TV shows like *The Dementia Choir* or the third season of *True Detective*; films such as *Still Alice* or novels like *Elizabeth is Missing* by Emma Healey (2015), and creates plays like *The Father* and *The Height of the Storm* by Florian Zeller. In *Still Alice*, the film of the novel by Lisa Genova (2015), the protagonist played by Julianne Moore is a linguistics professor; a less than subtle reminder of what she has to lose when words fail her. Zeller's *The Height of the Storm* mirrors the confusion of dementia by making the audience unsure who on the stage is alive or dead. In *Elizabeth is Missing* dementia is a plot device for the unravelling of clues to a murder. Dementia is something to fear but also something that can be used and exploited in numerous cultural permutations. Rather than being on the wings, dementia sufferers and their families have moved centre stage in culture, but without a concomitant social response to their 'forgotten pile of need'.

Dementia Care and Suffering

The demands of living with dementia or with a person with dementia have been charted in multiple contexts. In writing this book, we do not seek to downgrade the pain or fear that suffuse these narratives or the knowledge that the beloved person is

now different and seems like the victim of a cruel assailant. Indeed, our research has highlighted the suffering of families and friends:

It was the dementia that robbed her of speech... it's very difficult when you realise that they have sort of gone somewhere but the body is still there but they have gone off somewhere and it is not, it is still that person and you still love them very much but sometimes just a spark of recognition would be wonderful. (Elizabeth, Faye's sister, interview)

Their accounts also stress the lack of adequate care for those with dementia and the difficulties of negotiating the web of social and health services, of trying to find and fund the right care whilst knowing that none presently exists:

...speech declined, her behaviour got worse and I had no help at all of any sort, and um, eventually I just, just one day literally collapsed, I just couldn't do any more...The crisis team took her to a home but they kicked her out and she was taken to the hospital which was an inappropriate place for her to be, but it was the only place that was there. I didn't know what to do so I thought 'Well I had better have a look at care homes'. I didn't know where they were, I didn't know anything about that, I didn't know what to look for. So, I went up to the hospital and one of the nurses there gave me a sort of list of places that you know might be suitable and I literally drove round them and I think I had been to about seven or eight. I was in a state of agitation. (Peter, Stella's husband, interview)

In arguing for a posthuman perspective on dementia, we do not ignore the severe hardship suffered by those with dementia and their families, made far more difficult by structural issues of poverty, age, class and race. There are also tensions and ripples within family networks that can be prompted by dementia. Although our research

revealed exceptional acts of devotion, families were torn by the refusal of some members to accept the changes wrought by dementia or to take responsibility:

I have to say my sister is not even concerned about Faye really, it is very sad she did the old cop out of 'Oh I want to remember her how she was'...She said 'Yes, yes, yes, you do that you look after everything you look after her finances, you deal with social services and everything' which I suppose yes has changed the relationship. (Elizabeth, Faye's sister, interview)

Stella has four grown up children and sadly all bar one have turned their backs on her...the family, the family I thought I had now doesn't exist, so I have no support from them...It has been a very bitter pill to swallow to be honest. In fact, I am still swallowing that one. (Peter, Stella's husband, interview)

Dementia raises thorny issues about ethics and rights, about how issues of risk, responsibility and protection are negotiated, and these make everyday decisions extremely difficult. However, our research has also given such families hope that a different way of understanding and stimulating those with dementia can exist. It is this hopeful story that we wish to emphasise and explore, whilst not ignoring the pain that dementia brings.

Arts and Dementia

Our research was conducted in collaboration with artists from the fields of music, visual art and theatre. As such it contributes to a body of work that has shown the value of the arts in enhancing the lives of people with dementia. The major initiative in the UK was the *Created out of Mind* project funded by the Wellcome Trust, from 2016-2018. This was an interdisciplinary project that included scientists, visual artists, musicians, broadcasters, clinicians and carers. The project aimed to explore, challenge and

shape perceptions and understanding of dementias through science and the creative arts. It sought to 'develop novel toolkits, ways of conducting research, new questions and ways of thinking which enable us to better understand the role of and ways of using the arts with people living with dementia' (Brotherhood et al., 2017, p. 6). Allegranti has also made important and innovative contributions including using dance and public performance to work with young people with dementia and their families. Using a posthuman approach in her work, she believes that there are 'mutual entanglements that place artists, scientists, and therapists into a larger conversation that allows for material discursive ways of knowing' (2013 p. 402).

It has been well demonstrated that engagement with the arts is very beneficial for people with dementia: increasing social inclusion and intellectual stimulation (Camic et al., 2018). There are currently numerous studies exploring the impact of such arts interventions. However, they tend to take place in high-income countries in urban areas where there is easy access to resources; such interventions are understandably very limited in developing countries. These international arts interventions are varied: including gallery visits, visual arts, theatre, dance, creative writing, arts making, music making and singing (Camic et al., 2018, Burnside et al., 2017, McPherson et al., 2008, Harrison et al., 2010). Drama interventions have also been used with support workers in dementia care homes (Bolmsjö et al., 2012, Kontos et al., 2010) and have helped workers to reflect on their practice and be more aware of residents' body language. However, there have been calls for methodological innovation as many of these studies focus simply on what can be easily measured. Research 'must not be limited to the tools of the clinical trial model. Instead, researchers should rethink what constitutes rigorous and effective research for interventions aimed at creating a meaningful personal experience for the participant rather than measurable change'

(de Medeiros and Basting, 2014). This is a call to which our research studies respond. They attempt to do far more than simply measure impact, as we shall discuss, and although they validate the arts, our focus here is not the arts as such, but learning.

Lifelong Learning and Dementia

What distinguishes this book is that we place dementia within a context of lifelong learning and everyday creativity. Building on our previous writing, Quinn and Blandon (2017), one of our key arguments is that people with dementia can learn something new and that they should be included in any discussion of and plans for learning through the lifecourse.

There are three dominant conceptions of lifelong learning. First a neoliberal construction of lifelong learning has been used to promote an eternal treadmill of training and retraining in order to hold onto increasingly insecure and fragmented employment as retirement ages recede. Second, lifelong learning has connotations of privilege where wealthy silver surfers continue to engage in pleasurable learning through leisure. The World Health Organisation identified Education and Learning as key factors in social participation and a positive life as an older person (2002). 'It should not be a surprise that older adults need and want to learn. They want to stay interested and keep enjoying life to the best of their ability' (Boulton-Lewis, 2010, p.1). There is a third alternative vision of lifelong learning that is community based with social justice aims and that sees a potential and a right for learning in everybody at any stage of life and positions learning as the key to social transformation. Tett (2006), for example, has demonstrated the capacity for learning to change and resist oppression in older age, particularly amongst older women. At another level Wolf (2009) argues that learning enables older people to reflect on their knowledge and experience to make an important contribution to culture. In contrast to these three

approaches, there are posthuman critiques of lifelong learning (see for example Edwards, 2016) which recognise that it must be transformed to meet the demands of a posthuman world. However, people with dementia have not really featured within any of these visions of lifelong learning, including those that focus on social justice. Even the Report of the 2019 Centenary Commission on Adult Education: *Adult Education and Lifelong Learning for 21st Century Britain*, which seeks to re-energise and promote the field of lifelong learning, notes the lack of education aimed at older people (p. 38) but stops before any mention of dementia. People with dementia have been placed outside the realm of the productive, the pleasurable or the democratic.

There is scientific evidence that neural regeneration is possible through stimulation of the areas of the brain that have been damaged in dementia. Moreover, other areas of the brain can assume the memories and tasks that were damaged by disease processes (National Alzheimer's Association USA, 2007 as cited in Richeson, Boyne and Brady 2007 p. 724). However, most reference to learning has been to courses that train people to retain as much functionality they can have to survive (Richeson, Boyne and Brady 2007, p. 732) or leisure activities that help them reconnect with memories of the past (Cheng et al., 2014). It is the neoliberal discourse of lifelong learning as self-management that dominates (see for example Mountain and Craig, 2012). Asked specifically to speak about dementia and lifelong learning the Head of Research of the Alzheimer's Society in the UK had this to say about 'the learning that may happen after people have received their diagnosis:'

It is helpful to people in early stages of dementia to receive training in how to manage their disease, to be provided with strategies to overcome their difficulties, to be assisted in developing their own systems that can support them in managing their symptoms. (Sorensen, 2008)

‘Appropriate learning’ is thus couched as containment not expansion, with little sense of the openness to and from something new that constitutes learning rather than training. The European Association for the Education of Adults’ *Manifesto for Learning in the 21st Century* (2019) does mention dementia and highlights some innovative care homes in Norway and the UK. However, the emphasis here is still functional, highlighting staying independent and keeping active. This limiting perspective positions that person as outside of the innovative realm of learning, cut off from one of the vital agencies of life. Biesta argues ‘education is not just about the reproduction of what we already know or of what already exists but is genuinely interested in the ways in which new beginnings and new beginners can come into the world’ (2015, p. 5). Dementia is mostly positioned simply as degeneration and outside of the possibility of such generative states. Moreover, the possibility that people with dementia have much to teach others does not seem to be entertained in the literature.

Our interest in dementia and lifelong learning is part of our larger research agenda on learning outside formal education which recognises that learning need not be tied to any form of formal provision, that it is dispersed and profuse and can and does take place everywhere: in communities, in nature, in activism, in the home and in work and leisure of all kinds. Working with people with dementia has reaffirmed this vision whereby the potential for learning should never be discounted. Faye, for example, who has Down’s Syndrome, which is now compounded by dementia, has a history that is suffused with expertise and artistry that we can almost feel and touch:

Faye was trained as a weaver and she actually became a master weaver, she passed her exams and some of the weaving was actually sold in Harrods under her name, which is fantastic. She used to like colours, like what I would call moorland colours, like the smoky greys and the smoky blues and sage greens

and soft pinks and soft blues, that sort of colour mixed in with each other you know what I mean?" (Elizabeth, Faye's sister, interview)

In a postcolonial, posthuman, digital world the edifices of schools, colleges and universities are too limited to contain the profusion of lifelong learning. This untrammelled vision of learning also links to the breakdown of boundaries between disciplines and between fixed categories in other domains: the questioning of gender and sexual boundaries, the recognition of the hybridity of race and ethnicity, the acceptance that we will all at some point have a form of disability. The notion that gender and sexuality, for example, are fluid and on a continuum is not a new one, feminist and queer activists and thinkers have argued this for decades. Yet somehow these ideas now seem to have their day and are everywhere in popular discourse; if not necessarily always accepted nor free from bullying and hate. This willingness to recognise that boundaries are porous and borders artificial suggests that the time may be right to reframe dementia as another form of boundary breaking:

Borders are forever being crossed; to draw a border is to just demarcate a line across which we will carry dreams, wounds, meanings... (Solnit, 2019, p. 127)

Dementia as a posthuman way of being

A re-theorisation of dementia and lifelong learning requires a new theoretical lens and in this book we demonstrate the value of posthumanism, drawing on our previous work (Quinn and Blandon, 2017, Quinn, Blandon and Batson, 2019 and 2017). There are many and multiple forms of posthuman thinking: most influential to us here has been the work of feminist new materialists such as Rosi Braidotti (2013), Jane Bennett (2010) Karen Barad (2007) and Stacey Alaimo (2012). This has been coined PhEmaterialism by educational researchers (see Ringrose, Warfield and Sarabadi,

2018) and employed in research in early years, schools or Higher Education, but has had less influence in lifelong learning. In terms of exploring dementia, the key posthuman argument is that the 'human' is a construct that has its roots in Enlightenment thinking and is not an essential 'truth'. The humanist vision of what a person is and should be is formed of boundaries: a human is self-contained and either male or female, a human is fundamentally different from an animal or a tree or a machine; a human can think and can articulate what they mean in speech. Indeed, speech is repeatedly hallmarked as the distinguishing feature of a human whether that be in philosophical texts or popular fora. These categories position people with dementia outside the realm of the human: often they can't speak and they are not in control of their thoughts or body, they put themselves in different 'irrational' relations to the objects around them, they are not sure where they are. Rather than constantly seeking to restore people with dementia to their former state and to the anchoring of memory, we seek to validate their ways of being and explore them. As such, we focus not on them as individual selves but as parts of 'agentic assemblages' (Bennett, 2010). In trying to theorise dementia, posthuman ideas have proven interesting and valuable, but in line with previous writing, (see Quinn, 2013), we are alert to the potential problems as well as the possibilities they create and bring this critical lens to bear throughout the book. In Chapter Two, we discuss posthumanism in more detail (including some others who have used it to explore dementia), and draw out the ideas that we have found most useful in this book.

Dementia as a Feminist Issue

As Braidotti (2013) argues, being placed outside the category of human is a familiar experience for women. The construction of the human is a patriarchal one:

Under patriarchy the ideal body has been imagined as an isolationist nation, an island unto itself, in total control, which makes the female body-or any body whose orifices and interchanges, whose penetrability and vulnerability, are acknowledged-troublesome. (Solnit, 2019, p.131)

Dementia is a feminist issue, not just because the majority of those living longer are women and thus more likely to develop dementia, with 65% of people with dementia being female; but also because the construction of the uncontrolled body of the dementia patient, shares this disruptive force of the troublesome female body.

Faye is sitting and looking down, interacting with her body, touching her clothes and putting her arms on her large breasts. She continued pulling up the skirt so far. Touching her breasts as if she doesn't know what they are. (Observation fieldnotes)

Research conducted for the Joseph Rowntree Foundation in collaboration with women with dementia (Savitch, Abbott, and Parker, 2015), has indicated that the issues affecting women have not been well addressed; for example, the large numbers of older women living alone. The majority of those caring for people with dementia both inside and outside the home are also women and here the women's 'reserve army of labour' takes on new duties, often called up at a time of maximum negotiation of their own work and family life. The function of being in relation to dementia thus becomes an anticipated aspect of female life trajectory. Support care workers for people with dementia are often young working-class women with few qualifications or women migrants, and like any profession associated with women the work is demanding, low status and low paid, even though it is vitally important and a growing source of employment. As Peter says: 'they have a rough time of it you know, it's hard, hard

work.’ Higgs and Guilliard (2017) call for a wider contextualisation of dementia than that currently found in the health and sociological literature. They argue that it should be placed within the broader context of family life, the social imaginary, institutions of old age and the expansion of care work. We add that an intersectional feminist perspective on this wider context is crucial, making the work of black feminists such as Audre Lorde on illness, care-giving and resistance centrally important (1980). Although feminists have thought about age and its implications from de Beauvoir (1972) onwards a feminist perspective on dementia needs developing, and with it a political view of dementia that is more than campaigning, important as this is. In this book we seek to contribute to this development.

Our research studies

Much of the work using posthuman ideas in an educational context has been theoretical or has relied on small intense studies, with exception for example of Ivinson and Renold’s (2016) longitudinal work with young people in Wales. Innovative work exists in Early years (for example Somerville, 2016) and Higher Education settings (for example, Taylor and Gannon, 2018) but little in lifelong learning contexts. Having drawn on posthumanism in two smaller studies with older people in care homes and with women and children escaping domestic abuse (Quinn and Blandon, 2015 and 2016) we were keen to use these concepts in a larger study and to introduce them to a broader interdisciplinary audience of practitioners and participants. This book draws on the two research studies which then emerged. Both studies were conducted in South West England and took place in an area where urban deprivation sits within beautiful coastal and moorland landscapes. The first, *Beyond Words: a posthuman study with postverbal people* (Quinn, Blandon and Batson, 2017) was a longitudinal study. It took place over eighteen months and attempted to develop a posthuman

methodology. The second, *Making Bridges with Music* (Blandon, 2017) was a shorter study that built on the methodology and theoretical innovations of the first. Chapters Three and Four focus on these projects in detail and on what we can learn from them in terms of lifelong learning and dementia.

Beyond Words took place in a marine city with high levels of poverty and deprivation. It was an eighteen-month longitudinal study funded by Arts Council England as part of its first research grants programme. The aim of this programme was to bring together arts organisations and university researchers who already had established relationships to explore the potential social benefits of arts work. *Beyond Words* involved educational researchers from Plymouth University in the UK and Plymouth Music Zone (PMZ), a local community music organization. PMZ works with vulnerable adults and children using highly skilled music leaders who deliver a diverse range of innovative and tailored creative music-making activities. PMZ's work aims to empower individuals, families and communities through music. *Beyond Words* worked in conjunction with music leaders already employed by PMZ. It built on earlier collaborative research with older people in care homes and families escaping domestic violence to explore the following research questions:

How do we include and make music with those whose communication is non-verbal?;

What benefits do they and networks around them gain in terms of wellbeing/social inclusion?;

What role does the 'unspoken' play in inclusive music leadership overall?;

What are the implications of addressing the 'unspoken' for inclusive practice across the arts sector, how can this help practitioners in fields of Health/Education?;

How does posthuman theory, (which is interested in breaking down the dominance of the 'ideal human' as someone who expresses themselves through speech) help illuminate this process: what does this study add to the field of post-human theory?

The research was a mixed method longitudinal qualitative study of 16 months of music making with 25 people who either had dementia, acquired brain injury, autism or learning difficulties or were survivors of strokes. The unifying factor was that they were all deemed to be 'non-verbal'. The research explored their experience of music sessions which were held in residential care homes, centres for learning difficulties and the local organisation centre. The methods included weekly ethnographic observations, which aimed to trace subtle consequences of the involvement over time and 44 in depth interviews with participants' 'networks of intimacy' (Heath, Fuller and Paton, 2008) (family members and support care workers), which considered the lives of the participant and the perceived benefits of the sessions to their networks. Four focus groups were conducted with music leaders (and volunteers) to learn how they understand and approach working with the unspoken. Finally, visual methodologies in the form of 30 arts workshops were developed which took as a premise that participants' responses to music must be included through non-verbal means. The project also involved a participative seminar midway where interim results were discussed with diverse stakeholders, and it culminated in an international conference plus a celebratory event presenting the final findings to participants and networks of intimacy.

Ethical issues, including ensuring that participants understood what they were giving consent to, were important considerations for the project. This involved, for example, redesigning consent forms with visual rather than verbal information so that people with learning difficulties could understand them. For participants with dementia it was

necessary to contact and consult with those who had power of attorney. Researchers spent considerable time explaining in person the purpose of the project and how it might help those working in this field in the future to improve services to those who do not speak. In addition to obtaining consent, participants' assent was also taken into account during fieldwork iteratively, based on on-going feedback. The vulnerability of all taking part, including family networks and the researchers themselves, were carefully addressed throughout. All the participants have been anonymised in subsequent reports and articles. Consent has been given to use film of them in academic and research related contexts, but not in publicity materials.

Participant observations, and some filming took place during the delivery of music sessions in different venues. Observation prompts were developed which looked holistically at each session but also provided a posthuman and musical frame. They were developed iteratively with the ongoing fieldwork. They sought to address the following: bodies; communication beyond words; silence; interaction with things; space; time; group interaction; respect; responsiveness; forms of music making such as rhythm, timbre and pace; inclusion and becoming (of both researcher and participants). In addition, discussions between the researcher and the music leaders took place after some sessions.

Forty four in-depth individual interviews with members of networks of intimacy took place. The purpose of this was to explore the participants' lives with those who know them well and to understand from their perspectives what the music sessions were doing and whether they had any benefits to the networks who support each individual. This recognizes that each participant exists as part of a network or assemblage and is not simply an agentic individual.

Finally, as verbal interviews were not helpful for our participants, thirty arts workshops were run to allow participants to express their thoughts about the music sessions. The workshops were designed and delivered in conjunction with music leaders and support care workers; in some instances, family members also took part in the workshops. The mode of expression varied from large paintings on the floor, communal drawings and working with clay. The workshops were led by a practicing visual artist who was experienced in working in community settings. Music was used as a prompt, and to tie the sessions to the partner organization, this was provided live by a music leader.

The research team kept research diaries reflecting on meanings and issues thrown up through the research. For example:

I love silence and am always conscious of absence as bitter-sweet. Is this part of what we are exploring when we research what replaces words? (JQ research diary)

What is the meaning of a smile in an otherwise stoic silent face? Does a smile mean assent? Does it mean happiness? Does it mean agency? Or is it simply an involuntary contortion of facial muscles? (CB, research diary)

The project has generated large amounts of what Gale (2016, 2014) calls 'data events', a posthuman move away from a conception of data as something fixed and authoritative. As Ringrose and Renold (2014) argue, analysis is something that happens throughout a research project, as the affective pull of 'hot spots' alerts us to moments of significance and influences the direction of our thinking. So, for example, a focus on dementia and lifelong learning was unanticipated in *Beyond Words* but the pull of the data made it evident that this was something we needed to explore, as we shall discuss in Chapter Three. As well as our ongoing thinking and theorising, we

found it useful to focus on each participant as part of an assemblage and to analyse all the different forms of information within the assemblage. We started this process with a group analysis involving the two educational researchers, the head of music training from the partner organization and the project artist, bringing multi-disciplinary perspectives into play. The educational researchers then moved to a further close analysis using posthuman theory. In Chapter Three, we will focus on our work in this project with people with dementia and their networks, exploring what the implications are for lifelong learning.

Making Bridges with Music (MBWM) (Blandon, 2017) was a successive smaller study in the UK that was informed by the methodology and the findings of *Beyond Words*. This was a music and arts pilot intervention that worked with pre-school children and elderly people living in care homes in three deprived coastal towns in the South West of England. The intervention aimed to reduce isolation, increase self-confidence and community cohesion. It also wanted to identify CPD opportunities for care home and childminders and to create new music for the community. The intervention had two phases, the first phase included six creative weekly sessions with old and young people in three residential care homes. The second phase included an artistic response to be performed publicly as part of a local theatre festival.

The sessions were delivered by one music leader and several artists and used a combination of music-making, story-telling and arts methods to engage with participants. The visual artists used a rich variety of materials (such as paint, foam tubes, fabrics, stencils) to guide the creation of artistic artefacts, stories and songs. The sessions were also filmed by a visual artist. There were three nursing homes and eight childminders involved in the intervention. Each weekly session lasted a whole day and was divided into morning and afternoon sessions. The morning session

included preparation time for the intervention team. At 10 AM, childminders arrived at the nursing homes with the children to a designated room where everyone gathered and were given name tags; those who had not given permission to be filmed were identified by a different colour on their labels. The intergenerational intervention lasted approximately one hour and included music and art making activities, followed by a lunch break. Afternoon sessions included 60-90 minutes reflection time with the intervention team and time to review the morning footage and prepare for the following week. The team met with residents again in the mid-afternoon to share filmed moments from the morning sessions and to compose a 'song of the day' with mementos from the morning session. Children were not present in the afternoon sessions. In addition to informing session development and delivery, footage was used in the creation of a series of performances that were performed for the general public as a legacy of the project.

Observations occurred in two settings only because of budgetary restrictions. Setting One was a residential care home with 22 residents living onsite permanently with one person going in daily five days per week. The care home provided support to residents with diverse types of dementia and varied health care needs. In this setting, a core of eight residents attended the observed sessions; four childminders attended the sessions bringing in eleven children in total with ages varying from sixteen months to four years old. Setting Two was a larger residential nursing home with thirty two permanent residents. This Setting provided care to residents with more complex mental and physical needs; including people with advanced dementia and end of life care. Additionally, this setting had previous experience with an intergenerational garden intervention where some of the childminders and children were already known to some of the residents and staff members. In Setting Two, a core of five residents

attended the observed sessions; along with four childminders and nine children ages ranging from five months to four and a half years old.

The study used a mixed method approach that included both quantitative (ArtsObs Scale, Fancourt and Poon 2015) and qualitative methods (observations, intervention team's fieldnotes, researcher's fieldnotes, telephone interview with childminders, face-to-face interviews with nursing home workers, oral feedback from elderly and young children and a focus group with the delivery team). In addition, this study also captured interactions using the posthumanist observation framework developed in *Beyond Words* (Quinn & Blandon 2017). The posthumanist observation framework focused on interactions that prioritise situations that might have gone unnoticed in general ethnographic work. In Chapter Four we will focus on the data from this study that concerns people with dementia and discuss the implications for lifelong learning.

Conclusion

'Have you ever tried to enter the long black branches of other lives...?'

These are the words of the poet Mary Oliver expressing the desire and the difficulty of approaching forms of being that seem radically different. In this book we will try to enter the lives of people with dementia, to be with them, rather than claim to know them. In doing so we challenge the narratives of loss that surround them and use a posthumanist perspective to explore the 'potentia' (Braidotti, 2013), as in energy, vitality and resistance, that exists for lifelong learning in dementia.

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Chapter Two A Posthumanist Perspective on Dementia

Abstract

This Chapter introduces those posthuman ideas that we have found most useful in our research with people with dementia. These include: 'thing power', 'intra-activity', 'agentic assemblages', 'affinity', 'transcorporeality' 'submersion' and 'potentia'. We show how we have used them, drawing on 'data events' from our studies. The methodological issues raised by posthumanism are also discussed and our own practice critiqued. The Chapter also acknowledges that posthumanism does have limitations, for example in addressing the classed structure of dementia care. We discuss how a posthuman ethics has been addressed and present a posthuman ethics of rights for working with people with dementia. This suggests that lifelong learning for people with dementia is not a luxury, but a right.

Introduction

Posthumanism provides the theoretical and methodological frame for our studies and for this book. There are others who have used posthumanism to explore dementia, particularly Jenkins (2016, 2017) from a sociological perspective and Allegranti (2013) in an arts context, but none that we know of in education and lifelong learning. Both Jenkins and Allegranti have focused on people with early onset dementia and their families, whilst our research was conducted with older people in the very late stages of the disease.

There are multiple forms of posthuman thought and its theoretical world proliferates exponentially. It is a mistake to position it as radically new, as it builds on decades of feminist and queer theory and emphasises factors that have always been present in indigenous and non-Western thought. In this chapter there is no attempt to provide an

overview of posthumanism, rather an exploration of the ideas and approaches that we have found most useful and why. Rather than seeing people with dementia as less than human or formerly human, we show how a posthuman perspective validates them as posthuman, post-verbal: a new and potentially productive form of being.

Living in a posthuman/humanist epoch

A superficial sense that we are living in a posthuman epoch has gained ground and surfaces in popular culture, particularly in Science Fiction. Multiple factors such as artificial intelligence, body modifications or trans-gender awareness destabilise any sense of 'the human' as bounded, immutable or transcendent. In a digital landscape the enmeshing of person and machine has become normalised. Jenkins even argues that with the rapid development of technology and the cultural shifts associated with digital natives, in future dementia care might happily be trusted to machines and algorithms (Jenkins, 2017 p. 1494).

Nevertheless, in the West and Western-influenced countries dominant modes of understanding our world remain humanist. Neoliberalism, with its emphasis on individualism, competition, consumerism and marketisation very much depends on the idea/illusion of the individual human at the centre making things happen with will, choice and self-determination. Moreover, progressive conceptions of democracy, freedom and justice are also predominantly humanist. An easy shedding of humanism in search of a pure posthumanism is not possible. Humanism and posthumanism collide and co-mingle, it is not possible to disentangle them: 'we are already in the middle of the posthuman condition, its forces already entangled in the humanist fibre of our lives and thinking' (Taylor, 2016, p.7). This means that although posthumanism offers new possibilities, in Western contexts the person with dementia is still very much

constrained by the humanist assumptions of others and by the structures that emerge from that worldview.

Challenging the 'human'

It is the posthuman challenge to the normalisation and naturalisation of 'the human' that is most fruitful when considering people with dementia. Dementia breaks the unquestioned mould of the self-contained and rational human. Jenkins argues that moving from a belief in a coherent narrative of the self can promote equality in dementia care and promote 'people living with dementia as active facilitators of care in eternal process of becoming self' (Jenkins, 2014, p. 17). We argue that posthumanism helps us to move beyond any idea of self; even the kind of self envisaged by Jenkins. In posthumanism, the unit of experience is not the human but the 'agentic assemblage' (Bennett, 2010) and reality does not pre-exist but is perpetually reconstituted through the 'intra-activity' of matter (Barad, 2007). Consequently, the epistemological and ontological implications are huge.

As discussed in Chapter One, a humanist ontology does not have space for people with dementia, except as carriers of loss. Posthuman modes of thinking can provide a more productive way of entering and understanding their worlds. Rather than focusing on the inviolate individual who possesses a 'self' that s/he can communicate through words, posthuman theory moves away from the articulate human to focus on acts and bodies (Braidotti, 2013), on materiality (Barad, 2010) and the agency of things (Bennett, 2010). It validates and explores the significance of silence (Mazzei, 2016) and focuses closely on space and the visual in its methodology (Taylor and Hughes, 2016). As such it provides a positive and hopeful perspective on dementia. Working from this perspective validated our research participants and recognised other forms of living and learning that were not about speech or rationality but were equally

important. According to Braidotti, humanism has a restricted notion of what counts as human, it reduces the others, ‘the different’, to a less than human status of ‘disposable bodies’ (2013, p.15). The person with dementia is the ultimate ‘disposable body’ as s/he seems to have no place in the world. In this Chapter we show how posthuman theories help to rescue and value people with dementia; and we sometimes draw on fiction to elucidate these ideas.

Posthuman Theories

Thing Power and Vibrant Matter

When I can’t sleep, I think about the transparent glass box that is still stirring with life even in the darkness of night. That pristine aquarium is still operating like clockwork. As I visualise the scene, the sounds of the store reverberate in my eardrums and lull me to sleep. (Murata, *Convenience Store Woman*, 2019, p.21)

One of the most useful concepts for our research has been Bennett’s ‘thing power’, the notion that objects are not inert but make things happen. ‘Things too, are vital players in the world’ (Bennet, 2010, p.4). This is clearly demonstrated in the prize-winning novel *Convenience Store Woman*, where the shop comes to constitute the body and being of the narrator who works there. On numerous occasions in our research we saw how musical instruments exerted power, changed dynamics, prompted movement, not only for participants but also for ourselves:

The drummer was playing this beat that sounded like an alarm clock and he did it constantly, and it really annoyed me...I found myself getting restless and impatient, I couldn’t concentrate on my observations...the cacophony of the music (as it seemed to me) being played made me want to get out of the room. (Fieldnotes, Observations)

Whilst we might be used to the concept of the fetish object exerting an influence on humans, Bennett alerts us to the vitality of all objects; even those identified as waste.

On a morning walk she observes:

One large men's plastic work glove

One dense mat of oak pollen

One unblemished dead rat

One white plastic bottle cap

One smooth stick of wood

...I caught a glimpse of an energetic vitality inside each of those things, things that I generally conceived as inert. (Bennett, 2010, p.4-5)

Bennett focuses on what she terms 'vibrant matter'. Her argument is that both humans and non-human animals and matter all share a vibrant materiality and are teeming with life. A potent example of thing power in action is Emma Renold's (2019) 'ruler skirt', created as part of her research on sexual abuse in schools. Renold then wore it in numerous places and spaces as a message to policy makers and practitioners: it's sound a powerful warning, it's reading requiring a respectful bowing down.

In a humanist ontology, things are kept very much separate from humans, they do not occupy the same plane of existence. In contrast, the relations that people with dementia have with things is normally very much perceived as 'matter out of place', in that it disrupts this firm division. In our research we saw them try to eat musical instruments, physically attach themselves to soft furry objects, paint hands instead of paper or help themselves freely to any belongings they find on their wanderings.

Surprising conjunctions and intensities emerge where separations between body and external matter collapse:

Jane then moved to painting my hand with glue so I changed and got the paints so she could actually see the colour so she painted my hand and she really, really enjoyed it, really got into it and you could see her really working away at, at the different crevices in my hand and it was a really amazing experience as she became really relaxed very focused. (Helen, support care worker, interview)

In neglectful contexts the surprising approach to objects may lead residential homes to assume that they can be indiscriminate in their dealings with people with dementia and things:

It was seeing H (someone for whom appearance used to be of paramount importance) dressed in someone else's mini skirt and top that finally convinced me to move her to another home, even though she was quite happy herself and talking gaily on the telephone. I knew it would have mattered terribly to her once, even though now it didn't at all. Who was right? (JQ diary)

Such anxiety about the right relations with objects is not shared by people with dementia. In a sense they enact a posthuman 'flat ontology' rather than a humanist hierarchical one. For people with dementia things can matter tremendously (much more than humans) or not at all, and considerations of ownership, monetary value or usefulness don't seem to apply. Instead there is a direct engagement with matter. Sociological research on ageing, including dementia, has taken a material turn with more attention being paid to space and to objects. Buse and Twigg (2014) for example, conducted an interesting study into dementia and dress, including a focus on women with dementia and their handbags. This chimes with *Beyond Words*

where we observed a woman with dementia carrying a suitcase everywhere she went, and it also evokes a powerful personal memory:

I vividly remember a woman in H's home who always clasped a handbag to her.

'Look at this bag' she said pleasantly. 'It's full of blood.' (JQ, diary)

However, rather than seeing the handbag as such a macabre, uncanny object, Buse and Twigg explored them in terms of how they preserved a sense of identity and home. With a posthuman lens we see things differently, where the object has a power in and of itself and is not dependent on associations with 'the self'. Jenkins is interested in how a person with dementia can best be understood in a digital age. He draws on Haraway's (1991) vision of the Cyborg, but rather develops the concept of a 'symbiont':

As a person, a symbiont is a being that has achieved a state of mutually beneficial co-existence with other entities...they are not autonomous individuals but are defined through their mutual interdependence with other organic and non-organic beings. (Jenkins, 2017, p.1492)

This is interesting but still focuses attention on the person with dementia as a certain sort of particularised entity. We have found Barad's (2007) theory of 'intra-activity' more suggestive for our studies, as it posits that only at the moment of intra-activity do all forms of matter come into existence: and this includes the person with dementia.

Intra-activity and Agentic Assemblages: sparks of life

For Karen Barad the locus of attention is not on the individual, whether symbiont or human, but on the phenomena generated when different forms of matter are brought together. 'Matter is agentic and intra-active-generative not merely in the sense of

bringing new things into the world but in the sense of bringing forth new worlds' (Barad, 2007, p.170). The person with dementia is not a different form of matter than other humans, just one that exposes this process of intra-activity more clearly. The focus is not on words but on moments of communication, sparks of new life. The notion of 'new worlds' echoes with Biesta's 'new beginnings' (2015) and Deleuze and Guattari's 'becomings' (1984) as a chorus of possibilities that we follow in this book. So, a sparkly bangle does not pre-exist the moment that the person with dementia slips it on their wrist and neither does the person. She brings it into being as something pleasurable to flash and to wear and the bangle brings her into being as the wearer of the bangle who is happy and excited to wear it.

Moreover, such matter cannot be understood in isolation but as part of what Bennett calls an 'agentic assemblage':

Assemblages are ad hoc groupings of diverse elements, of vibrant materials of all sorts. Assemblages are living, throbbing confederations that are able to function despite the persistent presence of energies that confound them from within...Assemblages are not governed by one central head... Each member and proto-member of the assemblage has a certain vital force... but there is also... an agency of the assemblage. (Bennett, 2010, p.23–24).

Thus, instead of the isolated individual who speaks, the site of meaning is an assemblage which may include the human and may include words, but within which the human or the word may not be the most important element. Instead of positioning some matter as active and some as inert, a posthuman perspective sees and respects them all as having forms of agency.

It is useful to see the condition of dementia through this lens. People with dementia are often positioned, and even in the worst cases, treated, as inert lumps of matter.

They are moved into a space of detritus or waste. They are positioned as abject. For Kristeva the abject is something we reflexively flinch from: corpses, refuse or bodily fluids, something that we try to push aside whilst at the same time we cannot escape. 'It is something rejected from which one does not part, from which one does not protect oneself' (Kristeva, 1982, p. 4). In several instances during project interviews family members described, with grief, how children or siblings refused to acknowledge or visit their family member because they were no longer a person they could recognize, or indeed an entity worthy of continuing support. In some cases they were openly named as 'not there', even 'dead', or that the family was enduring what Ken calls 'a burial without a corpse'. Bennett's work shows how even material considered waste is 'vibratory' (2010, p.5), teeming with life and having agency in the assemblage and this is salutary in respect of people with dementia.

Silence and Bodies: 'how her eyes change'

In the *Beyond Words* project our focus was on those who do not speak or who have few words which can only be rarely used. An encroaching silence is one of the most challenging aspects of dementia, which seems to leave the person with dementia most alone and families and friends most stricken.

She was always surrounded by friends, she always had loads of friends, she was very caring if anybody was upset about anything she would be the first one there at their side and give them a hug and try to comfort them and then bit by bit as obviously dementia began to set in she became more isolated in herself.

(Elizabeth, Faye's sister, interview)

Mazzei follows on from other feminist writers such as Lewis (1993) in considering the function and nature of voice and silence in research contexts (see for example Mazzei

2007, 2016). Thus she draws attention to the silences that always occur in research interviews or the silences participants choose. She challenges the primacy of words as a mode of communication and with them the notion that they tell us something essential and uniquely personal about the person who speaks them. Moreover, she argues that voice does not belong to the individual but is distributed across the assemblage.

Because 'voice' cannot be thought as existing separately from the milieu in which it exists, it cannot be thought as emanating 'from' an individual person. There is no separate, individual person to which a single voice can be linked—all are entangled. In Deleuze–Guattarian ontology, there is no present, conscious, coherent individual who speaks the truth of her present or her past.

(Mazzei, 2016, p.158)

Consequently, in our studies we did not need to search for the individual voice or lament its lack but could trace how the participants spoke without words in their entanglements with other matter in the assemblage. Nevertheless, despite her interest in voice, Mazzei does not address those who cannot speak or who struggle to communicate with words. We have not found many studies, including posthuman ones, that do. Those who do not speak are commonly called 'non-verbal', but this automatically positions them as deficit, as lacking. Taking a posthuman position where 'post' is conceptualized as 'going beyond', we have adopted the term 'post-verbal' for our participants (see Quinn and Blandon, 2017, Quinn, Blandon and Batson, 2019). This helps to capture the sense that there are other ways of being and communicating that move past words.

Post-verbal people in our study may have a few words left but they do not use them in expected ways. As Spiro found in their study of singing in dementia,

‘memory for linguistic information contained in songs was superior but not limited to memory of old songs’ (Spiro, 2010, p. 893):

We noticed definitely in the dementia care home people who struggled to communicate hugely have retained an ability to sing most of the songs.

Yes, and sometimes with increasing stimulation with music will then be able to have some sort of conversation and might even communicate using a line of the song.

Little music conversation where they are kind of engaging socially but not necessarily in a chit chat way, but they are singing to each other. (*Beyond Words*, Music Leaders Focus Group 1)

Although they longed for their loved ones to speak, members of the networks of intimacy believed these post-verbal people communicate with their eyes and speak with their bodies and create deep emotional connections. Becoming attuned to this can be rewarding and revelatory.

...that’s something that Jane teaches me is being able to recognise her emotions from a very, very small window that’s you know maybe how her eyes change.
(Helen, support care worker)

Normative humanist constructions of the human place the body as subservient to the voice, but post-verbal people can lead us out of that destructive binary to pay full attention to the body and its capacities. Ironically, fiction, is sometimes the most productive creative space for thinking beyond words. For example, the collection of stories *Pond*, with its minute attention to the materiality of everyday life is a fertile source for thinking though posthuman ideas.

English, strictly speaking, is not my first language by the way. I haven't discovered what my first language is...I don't think my first language can be written down at all. I'm not sure it can be made external you see. I think it has to stay where it is; simmering in the elastic gloom betwixt my flickering organs. (from *Pond* by Claire Louise Bennett, 2015, p. 45)

There is a bodily language that cannot necessarily be understood in spoken or written terms and this is the realm of communication we explored in *Beyond Words*.

Affinity, Trans-corporeality and Submersion: visiting 'the bottom of the ocean'

As previously discussed, a humanist ontology places the human at the centre and sees each human as a bounded individual with their own unique self-hood. A fixed and integral Identity is perceived as 'natural' because this conception of what a person is has been profoundly naturalised by humanism and all its endeavours. Consequently, the person with dementia is positioned as unnatural and aberrant as they have radically changed and do not present a coherent self with safe boundaries. People with dementia reveal the porous relations that exist across different forms of matter. 'Neither One nor Other, that is what we all are and always have been' (Haraway, 2016, p.98). For Haraway, who now does not class her work as posthuman, but has influenced and been influenced by posthumanism, affinity has become the key concept in exploring the world and our only chance for survival, as we shall discuss in Chapter Five. Proceeding with a focus on affinities rather than identities is a productive way of entering the landscape of dementia and we explore this further in Chapter Four and our discussion of the *Making Bridges with Music* project.

Stacey Alaimo charts a further course with her concept of 'trans-corporeality', which explores the ways in which all forms of matter are enmeshed. 'The environment is not located somewhere out there but is always the very substance of ourselves' (Alaimo, 2010, p.4). Using the sea to think with, she invites researchers to 'follow the submersible' as 'submersing ourselves, descending rather than transcending is essential (to recognizing) we dwell within and as part of a dynamic intra-active, emergent material world' (p.283). A focus group with volunteers and apprentices at PMZ (who had themselves difficulty with speech through brain injury or autism) cast up a sea image that accords well with Alaimo's work. They face up to the fear caused by seeing the person with dementia as Other and show how submersion can overcome it:

As humans like we have a fear of the unknown...everyone I know a lot of people are afraid of the bottom of the ocean as they don't know what's down there, and so and so right if you encounter someone with a disability you have no idea like is there, is there, do they understand you?...so I think it all come from people's fear and most of the time you just have to put it out there...and then the whole fear just goes.

Trying to see people with dementia from above as 'bounded individuals' ignores their mystery: instead we need to immerse ourselves in their lives and their ways of being. This has methodological implications in that measurable 'outcomes' are not congruent with dementia and we need to change our perspective from linear patterns of progression to focus on intensities and moments.

Potentia: countering the 'semi-depressing environment'

Rosi Braidotti (2013) sees posthumanism as an affirmative approach and emphasises its capacity to release potentia: energy, resistance, vitality, which will destabilise egotistical humanism and stimulate new and productive forms of social relations. Rather than simply critiquing, she argues that we need to move and act to create something new. As an optimistic, and as some say 'utopic' (Ringrose and Renold, 2016, p.221), mode of engaging, potentia helps counter the individualised, even narcissistic, despondency all too easily caused by encounters with dementia. As Peter says about a dementia carers support group: 'It was all a bit of a nice semi sort of depressing environment where everybody was moaning and groaning about their own troubles'. If not for a faith in potentia, the capacity for lifelong learning amongst people with dementia might be hard to discern. As we shall discuss later in this chapter, Braidotti's position has its problems, but the uplift potentia provides has made our research studies possible. In Chapters Three and Four, where we discuss our research in depth, rather than measurable outcomes we uncover moments of energy and resistance: the 'new 'beginnings' (Biesta, 2015) of learning.

Posthuman Methodologies: 'this has her attention'

We are willing to cast a critical eye on our own practices as aspiring posthuman researchers. Methodological debates about how to engage in post-qualitative (Lather and St. Pierre, 2013), posthuman (Taylor and Hughes, 2016) research in education have already revealed both the difficulties and the excitements of this endeavour. As St Pierre (2016, p.26) asks: 'why is it so difficult to inquire differently?' Traditional ways of thinking and working are suffused with the centrality of an interpretable human subject. Giving up qualitative methodologies which rest on claims to know, interpret or represent human activities leads into 'formlessness, an inbetween-ness, a space that is not easily classified or categorised' (Holmes, 2015, p.9) which may be either

productive or dangerous. This space may be much more comfortable for indigenous researchers to inhabit (see for example Tuck and Yang, 2014), or for children as researchers (see Somerville, 2016) as their assumptions about what is real or meaningful may be much less fixed. For many, as Taylor and Gannon (2018) argue, talking about posthumanism does not always ensure producing posthuman texts or posthuman methodologies. The research we discuss in this book tried to develop a posthuman methodology and was 'always in response to call from something however non-human it might be' (Bennett, 2010, p.xiii). It paid attention to space, bodies, objects and was alert to what Maclure calls the 'glow' of 'non-propositional' data 'that have their ways of making themselves intelligible to us' (Maclure, 2013, p.661). It was such glowing data that led us to a focus on lifelong learning and dementia. Nevertheless, our projects did not always break free from humanist research practices such as individual interviews and focus groups. In practice posthumanism and humanism were entwined, for example in the observations in both studies which were ethnographic but paid close attention to matter and relationalities that are often ignored. Chapter Four discusses in detail how we developed a posthuman observation strategy that we used successfully in both projects.

To give one illustration, our strategy included close observation of how people with dementia communicate with their bodies. This is one rather satirical deployment of the body that was observed in *Beyond Words*:

Bodies: Stella was present in this session from the beginning. I can see that she moves her body, slightly but powerfully, to accompany some songs. In some songs she moves her shoulders forcefully and shakes the maracas and then she calms down again. This time, however, two support care workers came over to her and told her that they needed to take her away. They put a belt around her

to help her stand up. The support care worker tried several times, Stella seemed not to be co-operating. It seemed that she was making herself heavy on purpose, she did not want to leave the session, and she succeeded. The support care worker gave up and left her there in the session. Stella looked unperturbed. (Observations, fieldwork)

Stella cannot speak but she does have agency. Boyle (2014) does not ally herself with posthumanism, but she argues that current definitions of agency in social science, which depend heavily on rationality and language, need to be revisited and informed by the experience of people with dementia. In her research with five people with severe dementia Boyle found evidence to suggest that people with dementia demonstrate 'imaginative agency' (2014, p.1140) which might be 'habituated, embodied or emotional' (p. 1140). Our approach helped us to pick up these different forms of agency which do not fit normative definitions. It seems that often only lip-service is made to agency when it comes to people with dementia:

...you know there is in part of people's training when you are working with those people who have dementia you always ask 'Is that all right with you if I do that'... but you sometimes hear people saying that and you think 'I don't think I'd feel I had the right to say no, or could say no if I wanted to.'

JQ (laughs) 'Yes I know what you mean'. (Ann, Robert's stepdaughter, interview)

J is told 'No tears' when she comes back upset from a walk. Tears are disruptive to order in the care home and she is not allowed them. (JQ diary)

There is a troubling lack of respect, but people with dementia like Stella do find their own ways to resist, using whatever means available to them. One of the purposes of our longitudinal observations was to pick up on such moments of resistance.

In *Beyond Words and Making Bridges with Music* our research was about art in the sense that one focus was on how music or theatre might benefit our participants. According to Taylor (2016, p.19) posthuman research in education 'calls for new ways of finding out; to this end, posthumanist researchers lean towards data collection techniques that include arts-based, visual, sensory, movement, sonic and creative writing practices'. Allegranti (2013) in her posthuman research with young dementia sufferers and their families has used dance and public performance to successful effect. Jenkins et al (2016) used theatrical vignettes about living with early onset dementia to produce collective power amongst people with dementia. In *Beyond Words* We included a professional artist in our research team who was experienced in working with marginalised people. Her role was to work with our post-verbal participants to explore their responses to music and allow them to express them through art. Working in collaboration with a music leader she organised thirty workshops where participants used paints, pastels, clay, shadow play and film in response to music. The emphasis was on process, but products were celebrated and treasured, exhibited at the project conference and taken home at the end of the project. The arts workshops proved a contentious aspect of the research. For some in the music organisation it was the music sessions themselves that showed the impact of music, the art sessions were superfluous. For us it was important that the participants had a specific space within the research where they were engaging explicitly with our research questions, that they were actively included, not simply being observed.

The artist found working with people with dementia the most challenging aspect of the research. She raised questions about the ethics of working with people whom she felt could not respond. Nevertheless, pushed to continue and encouraged by the

developing findings of the study she found that the world of dementia was not the blank space she had feared:

I decide to try the textiles to see if she has a response. I get out a pile of different textured fabrics including some scarves, I separate some out and show them to her individually. She sits up and moves the chair much nearer the table. I pick up a scarf with some satin stripes and feel it near her encouraging her to do the same. Jane seems really engaged with the textures and yet doesn't touch them...As the Music leaders begin to sing *Yesterday* Jane takes a sparkly scarf and moves it around in her hand. Puts it down and picks it up again. Pulls it nearer to her and holds it above the table. She smooths it out and moves it around. This has her attention. (Artist's notes, workshop with Jane)

The intra-activity of Jane and textile produces something new. If conducted in a humanist context our research would engage with motivation: what was she thinking when she picked up the scarf, why did she do that? Such speculation would be futile, she can never tell us and if she did why would we assume it to be 'the truth'? In a posthuman context the focus is on what is created by the 'doing' in this case a moment of attention, focus and sensory engagement which tells us there is still intra-activity of Jane and the world around her. We shall illustrate this further in the next chapter.

Posthuman Ethics: a posthuman ethics of rights for dementia

How does posthumanism engage with the question of ethics? Although much emphasis is placed in the literature on Barad's (2007) ethical project, her debates tend to be disembodied. One potential solution is to draw on Alaimo's (2010) transcorporeal ethics. Barad argues that it is 'our responsibility, to help awaken, to breathe

life into ever new possibilities for living justly' (2007, p. x). Alaimo (2010, p. 22) helps bring this into sharp relief through the matter of toxic bodies:

Toxic bodies may provoke material trans-corporeal ethics that turn from the disembodied values and ideals of bounded individuals toward an attention to situated evolving practices that have far-reaching ...consequences for multiple peoples, species and ecologies.

The toxic bodies Alaimo foregrounds are women with breast cancer, but the person with dementia is also a body made toxic who delivers a relational ethics of rights and responsibilities. For Davies (2018, p.125) a posthuman ethics entails constantly questioning 'how are we dis/continuous with the world's injustices?' However, it is not only a question of what we ask ourselves, of our responsibilities, but of what is *demanded* of us. We will outline here what we call a posthuman ethics of rights. Working with people with dementia always raises ethical issues, which are normally presented in terms of human rights and are always problematic as they do not fit the assumed model of the 'human'. However, an ethical debate need not depend on the notion of 'human' rights, but on interdependency of all forms of matter; nor need an ethical position on people with dementia rely on their past or on their vestigial ways of being 'human'. In our posthuman ethics of rights all forms of matter (whether they are people, animals, plants, minerals, water) would have a right to actions that protect their survival and promote their flourishing. All those that have the capacity to take these actions would have a responsibility to do so. From this perspective, people with dementia have a right to lifelong learning and there is a social responsibility to facilitate this.

Posthuman Possibilities and Problems

As discussed elsewhere (Quinn, 2013), whilst posthumanism offers many possibilities, it also raises certain problems. Just as Braidotti's optimistic vision of the 'nomad' seemed to leave out the forcibly displaced (see Colley, 2010) so her joyful belief in 'potentia' needs to be tempered by recognition of all those forces that sap and distort 'becoming'. Her targets of 'the political economy of phallogocentrism and of anthropocentric humanism' (Braidotti, 2011, p.99) are at once too vast and not forensic enough. Braidotti has spoken of inhabiting 'my critical consciousness as a time machine which allows me to travel across different realities, or spatio-temporal coordinates' (Braidotti, 2011, p.107). This is what makes her writing inspiring, but it can skate over the messy parts of the here and now which we must attend to in addressing dementia and other social problems. Deleuze and Guattari, guiding spirits of much posthuman thought, argue for the rhizome as the metaphor for the mode of connection across disparate elements of life and not 'any structural or generative model' (1984, p.13). Explaining everything by underlying structure is seen to limit the complexity of the world and experience within it and to promote fixity rather than becoming. This is true but nevertheless, it seems clear that the care of people with dementia in the UK is structured by class. Better care, a more stimulating environment with access to arts activities are all dependent on money. Basic dementia care is basic indeed if not supplemented by extra income and so, as in housing or education, a stratified system exists. The Alzheimer's Society estimates that currently 25,000 Black, Asian and ethnic minority people in the UK have dementia. Little is known about how black and minority ethnic people with dementia are treated or whether and how sexuality is considered, but there is no reason to assume dementia care is any more free of racism and homophobia than other parts of society. Addressing the inequalities

of structure, however, would not free people with dementia from the narrative that positions them as formerly or less than human; only a challenge to humanist assumptions can do that. A socio-cultural awareness and a posthuman perspective may sit uncomfortably together but it seems both are necessary to understand how people with dementia are living.

Conclusion

In this Chapter we have explored the posthumanist perspective we have used in our research with people with dementia. In the following two Chapters we shall demonstrate in more detail the work we have done through this perspective in our two research studies. This perspective has opened our eyes and bodies as well as our minds; freeing up the ability to explore dementia as a potentially generative state of being where learning can happen. Furthermore, in developing here a 'posthuman ethics of rights', we argue that lifelong learning is not a luxury that can be graciously endowed on or withheld from people with dementia, but their right that societies have the responsibility to deliver.

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Chapter Three Dementia and the post-verbal

Abstract

In this chapter we use the posthumanist perspective introduced in Chapter Two to work with a range of ‘data events’ from the *Beyond Words* study involving post-verbal people with dementia and their close networks. We discuss and critique the primacy of ‘voice’ in lifelong learning, where it has been highly privileged. Instead, our research shows the significance of silence and the unspoken. We show how people with dementia have entered new worlds of kinship with other forms of matter, as part of agentic assemblages where words and the human are not at the centre. They are capable of becoming ‘new beginners’ through learning. Moreover, they act as teachers, illuminating new ways to understand bodies and time.

Introduction: *Beyond Words*

As introduced in Chapter One, *Beyond Words*, (Quinn, Blandon and Batson, 2017) was a longitudinal project which focused on people whom we have termed ‘post-verbal’: people with dementia, stroke, learning difficulties, autism or acquired brain injury. Working in collaboration with community music organisation Plymouth Music Zone, it charted the engagement with music of post-verbal people and their networks, and involved observations, interviews with family members and carers, arts workshops with the post-verbal participants and focus groups with Music Leaders.

Arts provision for what are usually termed ‘non-verbal’ groups appears to be neglected and under-researched, even though people who struggle to communicate with words, such as those with dementia, strokes and autism constitute a growing group with concomitant demands on health/social care and on the networks and communities around them. Sixsmith and Gibson (2007, p.133) found that music had a

‘communicative and stimulating effect’ on people with severe dementia and there is some limited research on the ‘non-verbal’ and music practice in dementia (Sherratt, Thornton, and Hatton, 2004, Sakamoto, Ando, and Tsutou, 2013). Unspoken aspects of arts practice like body language, spatial and visual environments, culture and ethos appear to be important aspects of inclusive music practice with wide applicability in all contexts across the arts sector, yet they are not widely researched nor understood. There is some research that connects non-verbal elements across music/dance (Karkou and Sanderson, 2006) and some that looks at non-verbal aspects of music leader’s practice (Silverman, 2008). However, only Lee and McFerran (2012) acknowledge that the music leaders’ non-verbal work contributes to social inclusion/wellbeing. We have not found any examples of longitudinal qualitative studies of the non-verbal in music and none such as *Beyond Words* that bring together a range of ‘non-verbal’ conditions.

People who are ‘post-verbal’ are not a different species and their struggles to be understood are ones shared with people who speak. One of the things the literature on communication shows is that barriers are common. ‘The issues faced by people with communication difficulties may not be qualitatively different from those that we encounter daily in negotiations with others’ (Grove et al., 1999, 194). Whilst people in late dementia are at the extreme end of the spectrum, they are not unfathomable creatures. In this book we use the work from *Beyond Words* that involved people with dementia and their networks to further develop our thinking on posthuman approaches to dementia and lifelong learning, building on earlier work (Quinn and Blandon, 2017).

Voice and Lifelong Learning

This chapter focuses on people with dementia who are 'post-verbal': as having moved beyond speech into other forms of communication. As such they disturb and disrupt the category of human, which has been dominantly linked to words. Rancière (2010), who is currently fashionable and influential in educational thinking, defines the human as one who possesses the ability to 'articulate language' and democracy as being open to all 'speaking' subjects. This positions those who struggle to use words forever on the margins. The idea of 'voice' is a dominant one in educational research, particularly in adult education. Under the seminal influence of Paulo Freire's *Pedagogy of the Oppressed* (1972), finding and freeing the voice of the learner is seen as an important pedagogical aim. Numerous lifelong learning texts unproblematically place voice as the goal; so much so that it would be invidious to highlight any one of them. The notion of 'voice' is tied to a humanist belief in an essential self who 'knows who she is, says what she means and means what she says' (MacLure, 2009, p.104):

Conventional approaches to educational inquiry often privilege the voice of the humanist subject, assuming that voice can speak the truth of consciousness and experience. In such paradigms, voice lingers close to the true and the real, and because of this proximity, has become seen almost as a mirror of the soul, the essence of the self. Educational researchers have been trained to afford authority to voice, to 'free' the authentic voice from whatever restrains it from coming into being, from relating the truth about the conscious self. (Mazzei and Jackson, 2017, p. 1091)

Whilst Mazzei and Jackson refer to educational enquiry more generally, we argue that voice has been given a special privilege in lifelong learning and the education

of marginalised adults; for the assumption is often that prior to education there has been a lifetime of enforced silence. As critiqued in Quinn (2010), the drama of voice is intrinsic to a liberatory view of lifelong learning: if silenced subjects can speak their truth, what Freire calls 'coming to voice', then this will be a first step to making them free. For Freire the emphasis is on a communal voice of the oppressed, but in lifelong learning literature voice tends to be presented individually as a triumph of the self. There are very many problems with this position. First, it ignores the fact that speech is discursively produced and consists of cultural narratives, it is not an individual possession. Second, the moment of speech is a performance not a truth for all time. Third, there is no direct conduit between feeling and speech and much of the affective domain cannot be expressed. All these factors mean that the mere fact of saying words is not a guarantor of anything. To rely on voice is simplistic at best and dangerous at worst, as it makes the individual and their utterance the locus of responsibility for change and not the structures that have shaped that speech. It is interesting that even posthuman research on dementia is not free from Voice. In their work with early onset dementia, Jenkins, Keyes and Strange (2016) explain that they use drama to 'give voice' to individuals whose voice has been marginalised (Jenkins, Keyes and Strange, 2016, p.80). Mazzei and Jackson (2017) position the voice as just one part of an agentic assemblage, not the central point. We also do this, for example by including the words of families, but there are two factors that distinguish our approach. One is the almost messianic positioning of voice within lifelong learning which adds a further layer of context and makes our challenge to the primacy of voice the more important. The other is the fact that our participants in *Beyond Words* mostly do not or cannot speak. They have reached the point of silence or as Ann says of Robert of 'the kind of sounds that have the cadence of

speech and might contain the odd phrase'. Words have a beauty and we value and try to respect these fragments, even when they do not seem to make rational sense.

We also focus on the unspoken and recognise that even if voice is absent the person still has a form of agency within the assemblage and their silence has a power. In 'Variations on a Right to Remain Silent' the poet and translator Anne Carson celebrates silence as a force that cannot be fixed or translated, a 'residue' beyond that which can be measured and known:

This residue, which does not exist-just to think of it refreshes me. To think of its position, how it shares its position with drenched layers of nothing, to think of its motion, how it can never stop moving because I am in motion with it...to think of these things gives me a sensation of getting free. (From, *Float*, 2016, pp.14-15)

Those very close to people with dementia are alert to this invisible 'residue' which others might perceive as emptiness:

Oh yes, I mean I am sure you know he is engaged with, he understands, I don't know why I say he understands...I mean, I think there is certainly at a level which is totally below words there is there is an emotional communication that is possible.

JQ: Yes, yes

I mean, I have no evidence for that except that I have seen it.

(Ann, Robert's stepdaughter, interview)

In *A Book of Silence*, Sara Maitland argues for silence as a form of communication. In her case it is sought voluntarily along with solitude, but her insights have resonance for our participants too:

Silence is a lack, an absence a void-silence is the negation of speech, and therefore of meaning and freedom...I go on being certain that this is wrong...Silence does not seem to be a loss or lack of language. It does not even seem to be the opposite of language. I have found it to be a whole world in and of itself. (2009, pp. 277-279)

In her silent work with Julia support care worker Helen gained 'a sense of stillness' that nourished her life beyond the care home. Through their engagement with *Beyond Words* the music leaders also came to an appreciation of silence and no longer sought to fill it (as we discuss in Quinn, Blandon and Batson, 2019):

Solo session with Robert. First, he was 'singing' along in tune...then he stayed silent for a while. He seemed relaxed...sitting back, hands resting on the side...Robert's body language did not change throughout the session, and it was the first time that I saw the MLs stay silent, letting Robert enjoy the silence. It was so quiet that it could have been uncomfortable, I wonder what the support care worker who was present thought of that silence. (Observations, fieldnotes)

In valuing silence and taking a posthuman position that argues against any notion of individualistic selfhood that can be un-problematically released in speech, this book tries to occupy new epistemological ground in lifelong learning.

Our Participants

We will look closely at the *Beyond Words* project and at the people with dementia within that project and the networks linked to them. Gaining access to people with dementia as research participants was not an easy process. Our potential sample was limited to those who engaged with the music sessions that PMZ ran in a care home. Within that, we had to identify people with dementia who were post-verbal and seek

permission from those with power of attorney to include them in our research. Initial written requests sent out via the care home received no reply and it was not until we went to a coffee morning and met families face-to-face that we gained agreement for a small number of people to take part. It is not difficult to understand the reasons why people did not want their family member involved in research. A desire to protect their privacy and dignity, a fear that the research might be disruptive or painful all would be legitimate responses. Building trust over time was a careful process but ultimately, we gained validation that our research was valuable and useful. A final celebratory event brought together participants and families to hear the results of our project and the support and confirmation we received for our work was truly rewarding. What we have is a range of data events gained through our multiple methods. Post-human methodologies increase our close attention beyond the single individual to the myriad forms of relationality in which they are embedded. Thus, although numbers were small, opportunities for exploration were multiple as we shall discuss. Another important factor to consider was that our participants were in the late stage of dementia, the stage beyond words. They were the most challenging to consider in terms of learning, but even at this point they had not gone beyond learning or teaching. Hence if the potential for learning can be perceived here, it must be even greater across the spectrum of dementia

New learning worlds: 'living in a different world'

...staying with the trouble requires learning to be truly present, not as a vanishing pivot between awful or edenic pasts and apocalyptic or salvific futures, but as mortal critters entwined in myriad unfinished configurations of places, times, matters, meanings. (Haraway, 2016, p.1)

The new landscape that people with dementia seem to enter is commonly seen as dystopian: nightmarish, empty and harsh. Memory work is therefore employed to drag people with dementia back to a safer place in the past. However, our research suggests there may be another way of thinking about the present that they live in:

You know there's no point, everything changes. My every preconception I might have of what she might or might not like has to be thrown out of the door, it is a new, she is living in a different world to that which she was, so therefore it is all new to her so therefore what I think her likes and dislikes are no longer apply. So, I have learnt an awful lot because of those sorts of things. (Peter, Stella's husband, interview)

In Stella's case, one of the interesting aspects of her 'different world' is a new set of affinities with non-human animals. A regular visitor to the home was 'the guinea pig lady' who brought in her guinea pigs for residents to touch and play with. Whereas once Stella hated and feared these animals, now she would delight in having them crawl over her. Although this may seem unremarkable, from a posthuman perspective this change is not at all trivial. In a humanist worldview 'man' is held as distinct from animal, especially through the power of speech. The consequence is that animals are disposable and subject to the will of humans, with disastrous results that are well known. From a posthuman perspective there is a flat ontology where there is no hierarchy of being and human and animal are always engaged in what Alaimo (2010) calls 'trans-corporeality'. Where once Stella held herself apart and above the animal, she now treats them as a form of 'kin'. 'The task is to make kin in lines of inventive connection as a practice of learning to live and die well with each other in a thick present' (Haraway, 2016, p.1). Whilst ties with human kin may be loosening, other forms of kin may be taking their place in Stella's

‘thick present’. Rather than plug the person with dementia into a retrospective world (which cannot work as they can never go back), we argue for recognition of the new world, as providing potentia: energy for new forms of learning.

Unending Lifelong Learning: ‘How Wonderful!’

As previously discussed, our perspective is that learning happens across multiple sites and spaces and across all ages. This dynamic view of learning means that those classed as non-learners or beyond learning are seen in a new light and their multiple forms of informal engagement are recognised and respected (see Quinn, 2010). Our research suggests that as well as providing heartache, dementia had allowed families to reassess past relationships, past synergies and the extent to which their family member had engaged in learning.

On first sight Robert, 89, seems lost in what his stepdaughter Ann calls ‘a hard place’. The detailed fieldnotes charting his observations over months are marked with many instances not of speech but of loud shouting and violent movement in his wheelchair. Like others in our study his relation to his body was unsettling, taking his hand to his mouth to lick his hand and fingers during quiet moments in the music session. The fieldnotes emphasise that he carries with him something that he is trying to catch hold of, ever out of reach. There is a sense of the uncanny: that Robert is in touch with something that is beyond the limited vision of those around him or on the periphery of sight. By moving away from the verbal (and the rational) he opens the field of vision. ‘There is no place that is not haunted by many different spirits hidden there in silence, spirits one can ‘invoke’ or not’ (de Certeau, 1984, p.108)

Robert makes loud sounds and screams and could be disruptive in the sessions... it looks as though he is hallucinating, trying to reach something/or someone, just beyond him. I was told by the home manager that he sings/makes loud noises all day long in his room listening to the radio, and I can surely hear him from the lobby every time... He often extends his hands in front of him, as if he were trying to reach something, to pick up something. He always looks down trying to collect that 'thing' beyond his reach. I see that in other residents too. (Observation fieldnotes)

It is characteristic of people with dementia that they often seem to challenge the dimensions of time and space that we normally use to make sense of our world. It is well-known that memories of today may fade instantly, whilst those of the past, particularly childhood, are hyper-clear. Visits from people who are long-dead are anticipated, whilst current family members are blanked. The uncanny realm that Robert seems alert to is one that enlightenment configurations have blocked off, but to which indigenous scholars and posthuman thinkers pay close attention. Tuck (2019) for example describes how she visits the cliffs of her tribal land in Canada and taps into the world of her ancestors; MacLure (2019) summons up the image of feminist researcher as a witch, attuned to the more than rational dimension. Both these educational researchers are alert to and in touch with other-worldly vibrations. Going beyond the rational and three dimensional is a posthuman aspiration; but people with dementia are already there. Finding a way to value this and possibly work with it is an important challenge.

Our observations noted that Robert's room contained photographs and books and an in-depth interview with his stepdaughter Ann brought Robert's lifelong love of learning clearly into view:

Throughout his life he has taken up interests off his own bat and entirely out of his own interest, he has taken up interests which he has then pursued. He was a great, a very keen cyclist, racing cycle, you know twenty-four hour bike rides... He loved fast cars, he loved motorbikes. He enjoyed learning things and doing things. He took up painting and wood-carving when he retired and did them to quite a high standard, but entirely off his own bat...He is a remarkable person, but you wouldn't look at it, because a lot of this I have discovered by going through his papers needing to get rid of things...

JQ: You didn't know those things, he hadn't told you about those things?

No, I mean he told us about his writing and things but (sigh) anyway.

JQ: How did he manage to learn by himself?

Well, he used to buy books. He did buy a teach yourself Russian set of tapes once, I don't know why!... To my memory he didn't ever go to classes.

(Interview Ann, Robert's stepdaughter)

Robert is thus a classic autodidact, one who has taught himself across multiple domains of interest, but who has kept this learning history to himself. It only comes into view once it has gone. From our point of view this is interesting in relation to lifelong learning, in that the scope of informal learning is hard to measure and such traces are valuable indicators of its proliferation.

Robert's stepdaughter Ann was very attached to him and visited the care home regularly spending time with him and talking to him even though there seemed to be little response. She took up an invitation to join a music session in Robert's room. Here two music leaders, one female, one male, took in a guitar, small shakers, a small

xylophone and a tablet with an app that could emulate the sounds of musical instruments. They sang songs and encouraged Robert to interact with the musical instruments, particularly the tablet. In her interview she described very powerfully what she witnessed:

He was very, very calm when they were there. There was an engagement at quite a deep level... I was amazed- they have a laptop (tablet) which allows you to play musical instruments. One of the things Robert took up and tried himself was the guitar, he used to go away and practice, he didn't have lessons, he just played it himself...It was this moving his hand across the laptop to make a sound there was almost a fleeting 'Isn't that wonderful' on the face...That is brilliant you are doing something creative in a way you can't be creative anymore.

JQ: I am interested in how it felt for you being there.

Oh I, to be quite honest I was almost in tears, and thinking about it I am almost in tears because what I was seeing was the Robert I remembered, the personality, the person is still there.

Her sense of joy on seeing this was then spread outwards as she returned home and immediately contacted all of Robert's family network:

I think it is a great comfort to us, it has meant a lot that what I saw is that the real Robert is still there even if we can't see it (laughs) not very often. I mean I don't think I doubted that really, but to have evidence of it was very, very um comforting to me to know that Robert isn't always in a sort of hard place.

The same session was also filmed by the project artist as part of the research and studied closely by the project team. Rather than focus on Robert as a bounded individual the attention was to the agentic assemblage of which he was a part:

Watching the film Robert's hands are clasped and no longer reaching. The fleeting moment of creativity seems to captivate everyone in the room. The musicians laugh gently with delight and there is a sense of benediction that seems to extend to everyone there. The people the instruments, Robert's face and body, the room with its flowers and photographs, the memories of the past forms an assemblage and every aspect has meaning. There are some words, but they are not at the centre of meaning. (JQ research diary)

Studying the film as a group containing the researchers, the music leader and the project artist was very fruitful. We explored the agentic assemblage of Robert's body, the room, the flowers, the books, the tablet, the music, the music leaders, the voice of Ann, the filmmaker, the researchers. Robert was not mute and inert but thrumming with life of the past and the life of the now. We focused more closely on the music itself. The 3:4 rhythm of the music was lilting and rocking, creating the maternal sense of a lullaby. Robert weaved in and out of the melody and matched the pitch of the notes played on the tablet. He was not a passive recipient of the music but a creator of harmony. The 'thing power' of the guitar and the tablet had powerful impacts upon him. The songs sang, 'My Bonnie' and 'The Skye Boat Song' were traditional songs of reaching out across the sea to something lost. We saw how Robert was simultaneously a little boy and a very old man.

Discussing whether the moment when his face expressed: "How Wonderful" could be called learning, we agreed that it was and it did not need to be repeated to be considered so or to be articulated in words. The project had shown us that time takes on a new dimension in dementia and that a lifetime of meaning can be compressed into a very short space of time. For Robert a moment was enough. Indeed, Ann's interview showed how Robert had pursued new learning throughout his life and then

put it down, he was never outcome-oriented and he never sought formal teaching or accreditation. His moment of wonder was one of a lifetime of new beginnings and becomings: with a ripple effect that even extended to the USA. On the basis of what she saw, Ann encouraged her uncle to introduce similar music sessions into care homes there.

We argue that Robert was learning and that this was continuous with his lifelong learning. Although there may always be scepticism amongst some, in discussion with other researchers there has been broad recognition of the validity of this claim. Previously, Robert did not know that a tablet existed or could make music. At that moment he did, and he engaged with it. Doing so gave him pleasure which he communicated to others. The learning process, which Biesta (2015, p. 5) defines as a 'new beginning', had been ignited. It is interesting to compare this moment of spontaneous and joyful learning with an enforced moment of jollity noted in our observations:

After several failed attempts to incite Robert to play the bells by himself, the support care worker took his left hand and guided him to touch different bells to produce different sounds. The support care worker kept on saying "Isn't it nice Robert? Well done Robert; you enjoyed that Robert didn't you?" I thought I heard Robert answering "No" to one of those questions. The bell playing stopped when Robert made a loud sound that indicated he did not want to do that anymore. (Observation fieldnotes)

There were several moments like this when care staff tried to push residents into engaging with the music or the arts sessions, against the wishes of the musicians or the artist. Learning does not happen when someone is forced or patronised:

conditions need to be created whereby the desire to engage is created. Like any successful pedagogical move, facilitating learning in dementia is a subtle process and space, things, affect, all play a part. Music can be a conduit to learning because, as Peter says, 'it attaches', but only if it is employed with care. We discuss the strategies employed by the music organisation in depth in Quinn, Blandon and Batson (2019) and argue that respect, responsiveness and relationality are the keys to successful music work with postverbal people.

Although we wish to claim Robert for lifelong learning our existing educational vocabulary is stretched and challenged by his experience. In discussing this process, we need to abandon our accepted language and preoccupations, as Robert will never be able to describe this experience to us and neither can it be explained away in any well-formulated way. We need instead to look at what Robert is doing not just as learning but also as a form of material poetry formulated through the body (see Quinn, 2016). The eye, the light, the expression, the delight, tells its own story. In Barad's (2007) terms neither Robert nor the music are the matter under question, rather the moment of intra-activity, what happens when the two come together is the real object of enquiry. The message of the spark is that something vital is happening that moment and that moment cannot be erased. This has nothing to do with managing dementia but everything to do with living and learning.

Teaching through dementia: 'I don't know what it is, but it is something.'

As we noted in Chapter One, we are positioning people with dementia, not just as learners but also as teachers. The lessons they had to teach were ineffable but profound ones. Turning to Jane, she is only in her sixties with a young but anguished face. She constantly paces around the home and she does not speak:

Jane seems confused, lost... sometimes she makes gestures as though she is going to start to cry. I can see that she is breathing rapidly as though she has realised something terrible has happened. (Observation fieldnotes)

In her silence and sorrow she has a strange dignity that is powerfully affecting. For support worker Helen 'she is the only one that has made me cry.' She does not seem to be present at all and indeed all her children have decided that she is 'dead', leaving only her husband to visit her. It was very difficult for her to stay seated during the music sessions, especially when powerful instruments like the drum were used. As discussed in Chapter Two, it did not seem hopeful that the planned arts workshop would manage to get her attention.

Nevertheless, the artist designed a session where musicians played softly at the periphery whilst Jane was encouraged to play with chalk and with different textured materials. The artist had found that music and arts materials had linked textural qualities which she felt would be useful to exploit. The session was filmed and as researchers we found watching it deeply sad and troubling. Jane's face as the musicians sang 'I wish I was Homeward Bound' produced an indelible picture of sorrow, made worse by our knowledge that in the early stages of her disease she constantly roamed the village where she lived, searching for 'home'. It was hard to put the feelings into words, but our bodies responded with tears at the time and feelings of distress and troubled dreams through the following days. As posthuman researchers we 'know' that the body tells us something important but here we felt it and lived it. We were feeling *with* Jane, more than thinking about her. Ringrose and Renold (2014) discuss how analysis is a continuous affective process and not something that is neatly contained within a fixed period. As opposed to the linearity of logic, Jane foregrounds and leads us into the affective domain.

For much of the session, Jane touched the materials but did not seem to connect with what was happening, but finally she turned and looked with some recognition at the musicians. She fingered a sparkly scarf with interest and when she was taken away by a carer she put the scarf around her neck and wore it walking away. For Jane to pay this much attention was remarkable and it taught us something about materiality. Words were gone but matter still mattered. The thrust of Karen Barad's work is to argue that matter makes things happen and here we saw this in action.

Understanding time and meaning differently: “stimulating the bubble”

Jane also teaches us a different sense of time. Her moment of sparkliness might be an instance of what Erin Manning (2016) calls ‘the minor gesture’. For Manning the minor gesture works against fixed notions of time. She describes the weather pattern of the coming of autumn and a sense of the associated colour ‘red’ as a minor gesture, connecting us to this time now and to all the times we have experienced it in the past. As previously shown in Chapter Two, fiction can help to illuminate such elusive posthuman concepts:

Olive Kitteridge was eighty-two years old and thought of herself as absolutely ancient...but she could feel the early-morning sun and sensed the beauty of the leaves that were turned already to a bright red at the tops of the trees. (from *Olive, Again*, Strout, 2019 p. 196)

The minor gesture is ‘a gesture felt in the event both as absolutely singular and infinitely multiplicitous’ (Manning, 2016, p.65); ‘the felt experience of potential’ (p.75). Working with Jane attuned us to this more fluid sense of time and meaning. Humanist conceptions of time and education are linear, working always towards the future and a perfecting of knowledge and the person:

For years I was more focussed on my career and that sort of thing, because we had a purpose, we were sort of going to get to a point and then we were going to go off and see the world...The nightmare is that we never saw this coming, never saw it coming. (Peter, Stella's husband, interview)

Dementia crashes into humanist time, breaks it, reveals its fantasy. A posthuman sense of time is a spiral moving backwards and forwards. Dementia makes observers more conscious and reflective of living within this spiralling time:

There's lots of things obviously, I mean anybody, anybody's life there are things that are bad and traumatic, and I do often wonder if they come, if they are stuck in your mind, do you know what I mean? And like, or even good things...those sort of little things that sort of come back, do you know what I mean? We all have them don't we in our pasts and these things just have a habit of just coming back. (Marie, Stella's daughter, interview)

As Deleuze and Guattari say, art can crystallise an ineffable moment: 'even if the material only lasts for a few seconds it will give sensation the power to exist and be preserved in itself in the eternity that exists for that short duration' (Deleuze and Guattari, 1984, p. 166).

...when you visit the dementia lounge they have no sense that you are coming every week, or that you have probably been before...so every time it's like afresh so if something happens to keep that group energy, it is interesting to see a person stripped back to just a moment, they are always in that direct moment of time and I think it is the music that draws them in...I don't know what it is, I don't know what it is but it is something.

...It is their access to what, you know, you are bringing: that creative energy.

(Music Leaders focus group 3)

When time is “afresh” a moment such as we witnessed with Jane can hold intense meaning. Jane’s husband put this perfectly in his interview when he stressed the value of music interventions:

Why give up? You shouldn’t give up. ...how you quantify the benefit that they derive from these visits is just impossible, apart from that moment in time when perhaps they may just react, that is excellent and then an hour later or minutes later they won’t remember that someone was there and they reacted to it, but in the moment, that bubble, why not stimulate that bubble?

The ‘bubble’ matters, it is not empty and meaningless, and neither is Jane. They both deserve our complete attention. The claim is not that Jane is learning something new, but rather that she is teaching us some important lessons about what we need to attend to and how. In this sense we posit people with dementia not just as learners, but as teachers too: as they reveal the fluidity and non-linearity of time and the significance and value of the moment, which lies beyond easy measurement. Similarly, ‘stimulating the bubble’; recognising that learning is possible and facilitating it, needs to become an integral aspect of dementia care.

Conclusion

‘Here in my head, language keeps making its tiny noises’

In this poem ‘Stars’ Mary Oliver is frustrated by the limitations of language and aspires to move beyond words so that she can ‘listen to the river, to the hawk, to the hoof’. In this Chapter, we have tried to capture meanings that exist beyond language and suggest that post-verbal people with dementia have much to teach in this regard. They may be considered ‘not there’ but the somewhere else they inhabit is not an empty

world and can offer new opportunities for kinship. Arguing against the dominance of 'voice' in lifelong learning literature, we have shown moments in which post-verbal people with dementia learn generatively and even teach; suggesting that it is no longer acceptable to leave them out of lifelong learning.

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Chapter 4

Intergenerational Learning and Dementia

Abstract

This chapter focuses on the learning that happens in an intergenerational music and arts intervention with pre-verbal children and elderly people with dementia. It draws on qualitative work using a posthumanist framework of observations exploring the embodied engagement of children and elderly people with instruments, space and each other and the learning that occurred during those intra-actions (Barad, 2007). Drawing on Barad's agential realism (2003, 2007) and using a posthuman observation framework (Quinn & Blandon, 2017), this chapter aims to reclaim notions of beginning and becoming in dementia. Using posthumanism as a navigational tool (Braidotti 2013) and using ideas of affinity not identity (Haraway, 2016) this research shows that it is possible to learn in dementia.

Keywords

Posthumanism; intergenerational music and arts interventions; dementia

Introduction

We live in desperate times; we live in hopeful times. It all depends on whom you ask.

As we discuss in Chapter One, popular perceptions of dementia are devastatingly negative, despairing and pessimistic often referring to those living with dementia as 'the living dead' (Behuniak, 2011). Yet, at the same time, landscapes of dementia are changing rapidly in the 21st century. In recent years, scholars in ageing studies have begun question the notion of an older human as complete or autonomous. There has been a call to 'deprivilege the human and look to the non-human and more than human aspects of ageing' (Andrews and Duff, 2019, p. 47). Moreover, promising advances in medical technologies, increased effectiveness of medications, changes on diagnostic criteria and widespread sharing of lived experience of living with the condition are changing how people live with and perceive dementia (Jenkins, 2013, p.3). In this chapter, we join those voices advocating for new ways of thinking about dementia. Using a posthumanist approach, we explore new meanings of being and learning in dementia. We join Jenkins (2013) in questioning 'whether the promotion of individuality is legitimate goal for dementia care and practice' (Jenkins, 2013, p. 4) and, as discussed in Chapter Two, focus on intra-activity rather than selfhood.

Thus, with full acknowledgement of the enormous challenges a dementia diagnosis can have on individuals and families, in this chapter we continue to argue that there is still capacity to learn with and from dementia, if we position ourselves differently. As introduced in Chapter Two, to reposition ourselves in a more positive landscape of dementia, we use posthumanist theory as a cartographic tool (Braidotti, 2013) to help us navigate and explore new perceptions of being, memory and learning in dementia.

We argue that there are other aspects of learning with, from and through dementia that are important and relevant, not only for people living with dementia but also for those who live with and care for them. In this chapter, using an inter-generational arts and music intervention, we explore Barad's, Haraway's and Braidotti's posthumanist invitations to think differently about the potential for learning in dementia. Following their call to 'disrupt patterns of thinking that see the past as finished and the future not yet ours or only ours' (Barad, 2007, p. x), to seek affinity rather than identity (Haraway, 2016) and to experiment with non-linearity (Braidotti as cited by Strom, 2018); we use three case studies to illustrate that learning is still possible in and through dementia.'

I am lost inside.... My brain and my body weren't talking...' (Wendy Mitchell, 2018, p.30).

As eloquently described by Wendy Mitchell in her book *Someone I used to Know*, dementia corrodes the memory and disrupts the inner compass. However, despite her initial fears and progressing symptoms, Wendy Mitchell's story is a prime example of the learning that can occur in and through dementia. Wendy Mitchell describes her attempts to outsmart the condition, and how as her condition evolves, she also evolves with the condition. We proceed with her inspiration in mind.

Intergenerational approaches to Dementia

As introduced in Chapter One, dementia is an umbrella term covering a range of several progressive, neurodegenerative disorders that affect perception, communication and memory. People living with dementia can present psychological, behavioural and emotional symptoms, especially in the later stages of the disease (Cohen-Mansfield et al., 2015). They present issues with problem solving, language and perception and in some cases disruptive or 'out of character behaviours' (Alzheimer's Society, no date). Generally, interventions to manage dementia, especially intergenerational interventions, have focused on reducing social isolation and increasing engagement (Bell et al., 2018; Jackson et al., 2019; Lee et al., 2007), increasing wellbeing (Swan et al., 2018) and reducing stress (Greg and Singer 2011). In contrast, some intergenerational interventions have focused on the young participants and are delivered as a preventative measure for younger generations to encourage them to engage with older people, as rich social contact has been identified as a dementia risk reduction strategy in older age (Jackson et al., 2019). Interventions have also sought to change perceptions of ageing (Jackson et al., 2019, Lokon et al., 2012, Belgrave, 2011).

Within this context, music-based interventions in early years have focused on children's learning. Scholars highlight that music interventions create a space where children can take risks without fear of failure are key elements to learning (Tarnowski, 1999, as cited in Fox and Liu, 2012, p.58-59). In early years, musical experiences are valued for providing individualised learning opportunities (Beynon and Alfano, 2013, p.121). However, these findings echo similar results on the effect of music interventions with elderly people (Belgrave, 2011). In fact, music interventions in an

intergenerational setting can be a great equalizer; intergenerational learning can be beneficial to all age groups in sharing cultural and experiential differences for a richer understanding, acceptance, support and respect of themselves and others (Benyon and Alfano, 2013, p.128).

From a socio-cultural perspective, breaking down age stereotyping of one age group toward another is a significant non-musical but important social outcome of intergenerational interventions. Sixsmith and Gibson (2007) found that music interventions 'provided opportunities to be with other people and to take part in meaningful activities with others, often engaging with them using non-verbal forms of communication and interaction, such as touch.' (Sixsmith and Gibson, 2007, p.133). In this sense, music interventions, provided a 'medium for physical and emotional bonding between a person with dementia and his or her family and carers' (Gotell et al., 2000, Hubbard et al., 2002 as cited in Sixsmith and Gibson, 2007, p.136). The sociocultural context of the music listening experience (which is itself linked to the individual and musical histories) is often left out of the analysis; Hara suggests that 'a sociological approach would seek to address this drawback by looking in depth at individual experience with music in dementia care' (Hara, 2011, p.35).

In addition to social benefits, there is also evidence to show that intergenerational music interventions have positive effects on elderly people. Benefits include feeling valued, making an important contribution, and a sense of satisfaction (Beynon and Alfano, 2013, p.121). In terms of wellbeing, older participants have reported a perceived increase in feelings of usefulness as their participation in intergenerational programmes progressed (Marx et al., 2005, as cited in Belgrave 2011, p.504). Moreover, research suggests that musical memories may not be connected to deterioration in the brain relating to speech and language, raising the possibility of music as a non-verbal form of communication for people with dementia (Aldridge, 2000; Brotons, 2000; Hubbard et al., 2002, as cited in Sixsmith and Gibson, 2007, p.128). However, systematic reviews of the literature on music and arts interventions have found inconclusive results because of methodological problems across studies. For instance, many studies lack sufficient description of the interventions to enable cross-study comparisons and integration into practice (Robb et al., 2011, p.1).

In this context, research using posthuman theory in intergenerational interventions is scarce. By focusing on acts and bodies (Braidotti, 2013), on intra-activity (Barad, 2007) and the agency of things (Bennett, 2010), this chapter aims to move away from the idea that being is intrinsically linked to memory and vice versa. A posthuman approach validates people living with dementia, recognises other forms of being and learning that are not about speech and memory. It also seeks to challenge old certitudes regarding identity and subjectivity (Taylor and Hughes, 2016, p.19) and recognise the multi-faceted nature of learning (Martens, 2016).

In particular, our research uses Barad's concept of intra-action as it places the focus of attention not on the human but on the phenomena generated when different forms of matter are brought together. This is useful when the focus is on moments of communication and different ways of exercising agency. In fact, seeing agency not as

an attribute but as ‘the ongoing reconfiguring of the world’ (Barad, 2003, p. 818) is useful in recognising how people living with dementia interact with the world and learn moment by moment. Generally, the literature shows that intergenerational interventions try to give people coping mechanisms to deal with old age, with loss of memory and identity, rather than embracing the reality of it. Wendy Mitchell’s story exemplifies instead how she realigns her inner compass as she navigates the landscape of dementia. It shows that ‘memory does not reside in the folds of an individual brain; rather, memory is the enfoldings of space-time-matter written into the universe, or better, the enfolded articulations of the universe in its mattering’ (Barad, 2007, p. IX). In the following section, we discuss our posthuman non-linear approach to explore concepts of being and learning in dementia, which allows people with dementia to be as they are, rather than trying to retrieve what they were.

What do you do when you cannot trust your mind anymore? Become a spider.

Adopting a posthuman approach allows us to find new points of reference, new anchors when known landscapes disintegrate. Using posthuman theory as a navigational tool is useful in conceptualising alternative and ephemeral ways of learning. The intergenerational interventions used in this research, allowed us to observe people’s entanglements with other matter in the assemblage and the ways in which they navigated their increasingly complex landscape of memory loss. To become a spider means to always find new points of reference that allow you to anchor yourself and navigate (inner and out) space, even when your spider web gets destroyed time and time again. We argue that learning occurs when people living with dementia find the –sometimes ephemeral - anchors that allow them to be as they are while living with dementia. The destruction of your spider web, need not be the end of your being, of your journey, it allows for new ways to reposition yourself.

Making Bridges with Music (MBWM)

The intergenerational music intervention we discuss in this chapter highlighted the potential for learning through and with dementia. As described in Chapter One, *Making Bridges with Music* (MBWM) was a music and arts intervention that worked with pre-school children and elderly people living in care homes in three coastal towns in the South West of England. The intervention aimed to reduce isolation, increase self-confidence and community cohesion and identify CPD opportunities for staff (both childminders and care home staff). The intervention included two phases; the first phase included six creative weekly sessions with participants and the second phase included an artistic response to be performed publicly as part of a local theatre festival. This chapter focuses on observations conducted during the first phase of the intervention.

The research used a mixed method approach that included both quantitative (ArtsObs Scale, Fancourt and Poon, 2015) and qualitative methods (observations, telephone interview with childminders, face-to-face interviews with nursing home workers, oral feedback from verbal participants and a focus group with the delivery team). In

addition, we used a posthumanist observation framework (Quinn and Blandon, 2017), an innovative data collection tool that allowed us to focus on key posthumanist aspects while collecting and analysing data.

The Post-humanist Observation Framework: what does a smile ‘do’ not what does a smile ‘mean’.

Reassuringly, I am starting to see POF as a navigational tool. It guides me to follow someone in space, it forces me to focus on almost imperceptible intra-actions; it forces me to stay with it. It is taking away my certainties. I stopped asking myself what does *that* mean, and instead I started to ask what does ‘*that*’ trigger? (Researcher’s notes)

The posthuman observation framework (Quinn and Blandon, 2017) was developed in *Beyond Words*, as discussed in Chapter Three (See Table 1). In this context, focusing on participants interactions with things gave researchers insights into subtle ephemeral changes that might have gone unnoticed otherwise or would have been dismissed as insignificant. The POF was developed in order to aid researchers to position themselves as posthumanist observers. It allowed researchers to pay close attention to, highlight and retrieve observations using a posthuman epistemology.

The POF was developed in order to aid researchers to position themselves as posthuman observers. It allowed researchers to intensely observe how participants move in space, whether this movement caused any visible change in their relations with others or their body language throughout time. Within the context of the music intervention, researchers paid close attention to whether specific aspects of music (e.g. tempo, pitch, harmony) had any noticeable impact on participants’ body language or movements. For example, in certain parts of the intervention when the primary medium of engagement was things (e.g. musical instruments, toys, fabrics) the researcher focused on bodies and response to things and what those engagements brought to the surface. In this sense, by focusing intensely across participants, space and things, POF helps to reveal the multi-layered aspects of learning. In this light, the constant walking of a person in a room gives more granular detail of the learning that occurs during this ‘wandering’. It goes beyond participant observation as it intensely focuses on what comes out of the intra-actions with other parts of the assemblage.

In this light, we believe that the POF is a ‘transformative research framework’ (Kara, 2015, p.9) as it was developed in a research context that sought to change negative perceptions of learning in dementia by focusing on and highlighting where learning can still occur. According to Kara (2015) ‘transformative research frameworks are based on, and intended to promote, positive social values such as equality and justice’ (Kara, 2015, p. 9). In this light, by identifying relevant training opportunities for the staff involved in the intervention, by highlighting that people living with dementia are learning as they navigate their changing being, the research results have the potential to shift negative perceptions of living with dementia.

Table 1. Post-humanist Observation Framework (Quinn & Blandon, 2017)

	Description of interaction/Intra-action
Bodies	
Silence	
Beyond Words Communication	
Interaction with things	
Time	
Space	
Group interaction	
Responsiveness	
Respect	
Music making (rhythm, pulse, tempo, timbre, texture, pitch, melody/tune/harmony)	
Inclusion	
Becoming	

Furthermore, the POF provided additional insights on the overall impact of the intervention. Results from the ArtsObs scale (Fancourt and Poon, 2015), that measured the effectiveness of the arts and music intervention on participants' wellbeing, showed an overall positive effect on participant's wellbeing as judged by changes in initial and final moods. However, the POF was useful in highlighting ephemeral changes of mood as intra-actions occurred during a session. These intra-actions would not have been captured by the ArtsObs scale as it collects initial and final mood scores only and a few qualitative observations. For example, the POF aided researchers to focus on participants who were hard to engage in the intervention because they could not sit still (both young and old), but the POF captures vital moments of learning for both sets of participants. In this light, the POF is key in witnessing and capturing momentary actions and momentary learning that can transform negative perceptions of dementia and affect the world as the potential for learning in dementia is made visible.

The following section discusses how using a posthuman observation framework and a posthuman approach was useful in identifying different ways of learning with and through dementia.

Discussion: Can you remember the future?

This section focuses on three participants who were living with different types of dementia and who were verbal at the time of research. These three participants and their intra-activity with things, with others and in space highlighted instances of learning that occur through and with dementia.

Learning about, from and with Greg: 'There is something he forgot to forget' (Braidotti)

Greg stands tall in the enormous room. His voice powerful, resonant, thunderous. Singing from the heart; singing using a voice his wife of 30 years did not recognise. Braidotti defines *potentia* as energy, vitality; a desire to endure; as something that installs a positive power... Greg plays with the children he towers over, he sings, he hides and seeks, and finally, he seems to have found himself. Attending a weekly music session, those around Greg also discovered that he can sing beautifully; he can play and enjoy himself and he can let go. His wife says that music has unlocked something in Greg. Music, and playing with children, have brought to the surface something that Greg forgot to forget, and he is honouring that with all his might and smiles. (Researcher's notes)

As described above, observing Greg gave us insights into the learning that was occurring, not only about, but also with and within him. In the above observation, for example, this 'new' Greg that emerges from his familiar identity exemplifies a desire to endure in his new condition of living with dementia. It is *potentia* in action. According to Braidotti (2013), *potentia* disintegrates the ego (narcissism paranoia, negativity) and installs a positive power. Consistently throughout the intervention, Greg's playfulness and desire to immerse himself in the present shows how *potentia* helps us see and understand that it is not about focusing on what is lacking, but understanding that there other embodiments, other valid ways of being. Furthermore, his intra-activity others, with musical instruments and other objects (fabric, paper, toys) illuminates how Greg was constantly 'seizing to be' in the present. This desire to endure, to be open to a process of becoming is useful in developing conceptions of agency when working with people living with dementia.

Of course, as we discuss in Chapter Two, the agency of people living with dementia is a complex and serious issue. In interviews, carers reported that people with dementia are different every day and could deteriorate quite rapidly. What we are suggesting here is that we must be more alert to how people living with dementia communicate and using a posthuman approach can help us zoom in to where and how this communication is happening. Using Bennett's concept of agentic assemblages where she notes that matter cannot be understood in isolation (Bennett, 2010, p.23–24) was helpful in our observations of Greg as we focus on assemblages and all forms of manifested agency as the following observation describes:

The music leader started this part of the session using a baton. He instructed the audience to play their instruments very loudly when he raised the baton up and very softly when he took the baton down. He demonstrated once and all participants followed his instructions. He then, asked for a volunteer, and Greg jumped to his feet. Greg started directing with the original instructions, but a few seconds in, he started moving the baton with a flourish, as if drawing an 8 on the air. He swirled, and circled, and danced around the room, baton in hand, enjoying himself immensely, if the big smile on his face was an indication of happiness. After a few minutes, he passed on the baton to a little boy who continued to direct the group and Greg sat to play his instrument (a tambourine). (Researcher's notes)

This observation highlights how an object (the baton) carried the power to make things happen. In the observation above, Greg's use of the baton went beyond what was expected of him. Greg decided to twirl and dance as part of the exercise, he seized the moment. Moreover, looking at the whole assemblage: the music being played, the other people in the room, the instruments being played, the high spirits people were in at that point of the intervention; all these things allowed Greg to become a swirling director for a few minutes. In numerous occasions during the intervention, we witnessed similar situations where objects (fabric, musical instruments, toys) exerted power, changed dynamics, prompted movement in different individuals that were usually sedentary.

Thus, observing Greg through a posthuman lens was useful in highlighting the learning that occurred. Looking intensely at bodies, interactions with things and space has shed light on the possibilities for learning about, with and from someone living with dementia. In Greg's case, two staff members interviewed commented on the strong positive effect the music sessions have had on Greg. Every day at lunch time, he talked about the music sessions in detail. The carers were surprised he was able to remember so much. Moreover, they both commented that Greg's wife of 30 years was astonished to hear him sing; she had no idea he had such a beautiful singing voice. One care worker reflected: it is as if 'the music has unlocked something in him'. Indeed, music, the arts activities and relations with others and with things might have created the right conditions for new learning to occur, not only within Greg but also in others. Following Barad's lead, it helped us understand that we are not separate but entangled, that 'agency is not an attribute but the ongoing reconfigurings of the world' (Barad, 2003, p.818).

Learning from and with Bernard: intra-actions and the value of fluidity

I like how spiders fly through the space incessantly weaving their ways around. Their webs get destroyed easily, despite their intrinsic strength, but spiders don't give up, they start weaving as soon as their web is destroyed. They always find the right points to anchor the web, new coordinates in the space to launch them upwards, sideways. They always seem to find new ways to move in the space they are building their webs. They always find ways to anchor themselves. Just like Bernard. He roams the space in the care home, trying to find an anchor, a safe space. Perhaps that is why he always goes back to his familiar or favourite chair...

One day, the music brought distant memories of a boy rowing down a river with his father. Carers tell me that despite himself, he has made a friend who anchors him to the music sessions in different ways. Music seems to be the means that allows him to navigate in space and create instant beginnings; it allows him to find new anchors to attach himself to so he can move in the space dementia has opened up for him. (Researcher's notes)

Bernard moves through space like a spider. To everyone's eyes, Bernard roams the rooms and finds it difficult to stay still in one place. Observing him during the arts and music sessions gave other insights about his 'aimless' walking and the multifaceted learning that occurred as he moved through space and responded to things and with others. Observing Bernard, brings to mind Solnit's thoughts about walking:

...each walk moves through space like a thread through fabric, sewing together into a conscious experience... (Rebecca Solnit, *Wanderlust*, p. xv)

Wandering is something that is often deeply feared by people living with dementia and their carers as they experience 'intense anxiety about their risk of becoming lost' (Brittain et al., 2017, p.271). There appear to be two broad perceptions of wandering in dementia: a derogatory person-centred care approach that sees wandering as a problem and a second approach that sees it as a normal human activity. During the intervention, the first approach became evident as Bernard was not unusual in his roaming; fellow care home residents created some disruption during the intervention by their constant wandering in and out of the session. The intervention team were dexterous in managing itinerant residents, but carers made efforts to contain, or in some cases, exclude, them. The care workers were not alone in their despair however:

Session one: Bernard left the session 15 times today.

Session two: Bernard brought in his own Jew's harp and played to the group during the first part of the session. However, after this, he left the session 12 times.

Session three: Several times during this session, Bernard stands up ready to leave, but sits back down again. But after a while, he leaves and comes back again. In total, he left the session 10 times.

Session four: Same routine: Bernard starts the session sitting on his chosen chair and stands up to leave; sits back down again for a few seconds and then stands up and leaves; a total of 11 times today. However, the last time he stood to leave, the person sitting next to him said: 'sit down, it is not over yet mate!' Bernard sat down until the end of the session. (Researcher's notes)

In contrast to the negative associations of wandering, walking is perceived positively. Walking is an activity that brings numerous health benefits, produces an experience of place and is considered 'rational, mindful, controlled and cultured' (Brittain et al., 2017, p.272). In this light, posthumanist theory helps in shifting the negative perception of being unanchored from reality as a result of dementia, to seeing the person with dementia as a fluid subject capable of bringing forth new worlds (Barad, 2007, p.170). In Bernard's case, this fluidity and becoming goes beyond himself as others around him are affected by his intra-actions. Interviews with care workers provided further insights into the changes Bernard and another resident were experiencing after the intervention started:

The music sessions have had a good impact on some of the residents. For example Bernard is now good friends with [another resident], we didn't see that coming. We are all very pleased because, until the music sessions started, Bernard usually kept to himself, just walking around aimlessly. Whereas [Bernard's new friend] never came out of his room because he thought he did not have anything in common with anyone else in here. He is here because of his physical disability and needs support, while most people here have dementia or other mental health issues. It is lovely to see them meeting for lunch every day and talk more regularly during the week. [Bernard's new friend] comes out of his room more often. He has started to play the harmonica again, he said the music sessions have inspired him to re-learn it. (Care worker interview)

The care worker's observation provided a useful insight as to why Bernard responded to the comment: 'sit down, it is not over yet mate!' by sitting down, by anchoring himself. Here, Barad's notions of intra-activity are useful in highlighting the learning that is occurring. Barad believes that 'bodies are not fixed in space and time but are imbricated in processes of intra-active becoming'. She stresses that we cannot think about bodies as separate from the social and vice versa (Barad, 2007, p. 151 as cited in Doucet, 2013, p. 295). As reported by the care worker, Bernard's friend secluded himself to his room because he felt he did not find anything in common with his fellow care home residents. The music intervention provided conditions for people to meet and act outside their normal routines to learn something new, most importantly it created the conditions to highlight those 'processes of intra-active becoming'. Both men were brought together by these processes:

It was also clear, that Bernard preferred to sit in the same place in every session. He appeared distraught if someone else was occupying that space and would walk out of the session. It seemed to me that every time he came back in he was trying to find his anchor, his familiar point of reference. And it seemed that he found that point of reference in another person, an unpredictable friendship was budding. Throughout the music and arts sessions, Bernard started to engage slightly more, not with the group but with another resident. (Researcher's notes)

A posthuman framework allowed us to approach roaming under a different light and focus on the potential for learning that exists in roaming, not only for the wanderer but also for those with whom s/he comes in contact. In posthuman theory, the unit of

experience is not the human but the 'agentic assemblage' (Bennett, 2010), and reality does not pre-exist but is perpetually reconstituted through the 'intra-activity' of matter (Barad, 2007), just like a spider builds its web. In Bernard's wandering we see him in the present moment, we see him navigating the landscape of his dementia moment by moment. Braidotti believes that 'the present moment is both what we are ceasing to be and the seeds of what we are in the process of becoming' (Braidotti as quoted by Strom, 2018, p.184). We have learnt from Bernard that anchors matter, as ephemeral as they may be, as they allow us to connect with others:

Observing Bernard today brought to mind a scene from a nature programme I watched recently. The programme was about solitary mountain lions. They were beautiful as all felines are, they were the colour of sand. They fit in the rocky landscape perfectly, their colour camouflaged them well. The story was about a lioness and her two cubs. The narrator said that it will come a time where the cubs will wander away and will never see their mother again, although they will stay in the same territory. Except, that they will recognise their mother's scent if they came across it. The programme captured that very moment, when a grown cub was slowly wondering up the rocky mountain, as solitary as a mountain lion can be, and it suddenly stopped and gently sniffed the air. It continued walking slowly, elegantly, as felines do; and it suddenly stopped again, it lingered a little longer this time, but after a little while, it continued on. The narrator said that the grown cub had smelt the scent of the mother. If I would have been watching that lion without knowing the animal's capability to connect through scent, I would not have known that there was meaning in that act. It brought to mind Anaïs Nin's phrase: 'We don't see things as they are, we see them as we are.' (Researcher's notes)

Thus, through Bernard, we learnt two things. First, we learnt that wandering, as observed in people living with dementia, need not be perceived as negative. On the contrary, roaming is full of possibilities for learning if we decentre the human and look at the agentic assemblage. Second, there are opportunities for learning for carers and family members if notions of dementia shift to tell a different story. If we begin to see things and people as they are, instead of clinging to what we think they are; it would have an impact on how we support, not only people living with dementia but also those who care for them. For the reasons discussed above, posthumanist thinking is useful in addressing the fears and anxieties that wandering in dementia brings. A posthumanist perspective on wandering would highlight and echo Solnit's characterisation of walking and apply it to dementia:

Walking, ideally, is state in which the mind, the body, and the world are aligned, as though they were three characters finally in conversation together, three notes suddenly making a chord. (Rebecca Solnit, *Wanderlust*, p. 5)

Learning with and from Sarah: ‘That bit is the words’: learning beyond memory and identity

Initially, Sarah appeared to be not ‘quite there’, not present, her eyes glazing over the room. However, Sarah started to respond as the music and arts sessions developed. She started to interact with children more, especially when interactions were facilitated by diverse objects (instruments, fabric, cuddly toys)...

[In the third session] the music leader went around the room handing out the lyrics of the song they were about to sing. Sarah took the page and placed her on her lap. One of the children came over to her and looked at the page and then looked at Sarah. The music had already started and Sarah took the page up – upside down- and pointed the lyrics to the expectant child- and said pointing at the lyrics: that bit is the words. (Researcher’s notes)

The way in which Sarah engaged with the lyrics in the above observation could be attributed to either sight loss, low disposition to engage or a lacking capacity to read. However, observing Sarah as the intervention progressed presented a different perspective on her actions, especially as her memory was deteriorating rapidly. Although, initially, Sarah seemed disengaged and distant and was passive in interacting with children, her attitude and body language changed significantly during the arts and music intervention. In the moment described above, Sarah is confidently transferring the knowledge she has: ‘that bit is the words’. In that moment, it was irrelevant whether Sarah could or could not read the words, what the child might do with that information, or whether the information was useful. There was potential for learning for both Sarah and the child. This potential for learning might seem insignificant, but we argue that small cumulative opportunities for learning matter. Braidotti believes that it is important to nurture intergenerational connections not only for continuity of knowledge but also to create alternative knowledge (Braidotti as cited by Strom, 2018). Observing Sarah and her interactions with young children through a posthuman lens highlighted the learning that children, childminders, elderly people and their carers were experiencing.

In interviews, childminders and care workers reported that they have found unexpected and useful knowledge by observing the relations between the young children and the elderly. For example, they highlighted that the intervention created opportunities for both, young children and the elderly, to experience a reversal of roles from being cared-for to being a carer, a rare experience for both groups:

It was lovely to see the children having the confidence to show the residents how to play the rain maker and the xylophone. I think this is very good for the children as they normally don’t have a chance to ‘teach’ something to someone, they are the ones being taught. (Childminder interview)

I have learnt so much about [participant]! I had no idea he loved steam trains so much for one...seeing him interact with [child] has been a revelation The intervention has been helpful in showing us what people are still capable of doing instead of focusing on what they can't do anymore. (Care worker interview)

More significantly, childminders and care workers reflected on the similarities between the young children and people living with dementia. They reported these reflections impacted on how they deliver care to both groups. Some of the commonalities between the young children and people with dementia included:

- Enjoy repetition (songs, rituals, routines)
- Can become poorly frequently
- Enjoy simple things
- Speak the truth, no social filter
- Don't know the time of the day
- Get tired very quickly and need to sleep
- Have the capacity of being in the moment
- Moods change quickly without giving any warning
- Lack of inhibition that allows them to explore and learn new things

By identifying this common ground and applying this knowledge, practitioners and carers echo the importance of focusing on affinity instead of identity (Haraway, 2016, p.16). Within the intergenerational context of the intervention, it is also possible to see how identities (based on age and dementia diagnosis) seem 'contradictory, partial, and strategic and we need to aim for 'a coalition though affinity, not identity.' (Haraway, 2016, p.16). In the context of learning, these thoughts are helpful as they move beyond thinking in terms of the identities of young children and elderly people with dementia. Moving beyond identity and self helps to remove negative and limiting barriers. Thinking in terms of affinity 'helps us go beyond the mechanisms that shape bodies and experience and force them into identity categories' (Braidotti as cited by Strom 2018, p. 183).

Furthermore, support workers and childminders involved in the intervention also reflected on their learning following the intervention. Both groups admitted to having initial preconceptions that the children were curious (always looking to the future), whereas the elderly people, especially those with dementia, were wishing to look back to pick up the pieces of a shattered, lost identity. However, by the end of the project, both groups acknowledged that these two groups of participants have several things in common: that the elderly were curious and the children were using their memory. For example, there were numerous occasions during the intervention, when elderly people, both with and without dementia, were curious about musical instruments they had not encountered before (e.g. rainmaker, xylophones, calabash shakers). The elderly were also curious about new songs the children were singing that they had not encountered before. From the children's part, childminders reported on the connections some of them had made with a few residents. After the intervention, and throughout the week, the young children would comment on what the person was wearing or describe certain physical characteristics. In this light, childminders and

support workers reported that these observations had an impact on their perceptions of age and learning.

Moreover, one support worker noted that taking part in the intervention made her reflect on notions of inter-dependence. She reflected on how the intervention allowed her to notice how the young and the elderly participated as equals and allowed them to explore in the moment without judgement. In this instance, using posthuman theory provides 'rich ways of thinking about the inseparability of body-social linkages and care-giving relations between carers and the cared-for' (Doucet, 2013). By acknowledging that people with dementia can learn and can teach us something, we move away from coping mechanisms, from containing the damage of the disease. Posthumanism reminds us that 'repair work is not transformative' (Braidotti as cited by Strom, 2018) and that there is a need to seek transformative knowledge that moves us away from fixed ideas of identity, loss and ageing towards ideas of affinity and new ways of learning.

Conclusion

In this chapter we have reflected on the multi-dimensionality of learning that occurred in the intra-actions of young children and elderly people living with dementia, when they took part in *Making Bridges with Music*. Current perceptions of a diagnosis of dementia are closely associated with a death sentence. Using a posthuman approach, this chapter aimed to shift negative perceptions of dementia by highlighting the potential for learning that exist in, through and with dementia. It also showed how posthuman theory can be helpful in understanding dementia. Using three case studies of people living with dementia, we sought to stir conversations on 'how to have a dynamic vision of pain' (Braidotti as cited by Strom 2018, p. 184).

Furthermore, this research showed that capacity for learning is omnipresent in dementia. A posthuman approach is useful in identifying opportunities for learning as it decentres the human and focuses on assemblages and intra-actions. It recognises that 'people are not separate from their environment but entangled and that we need to look at their location in relation to multiple others' (Braidotti, 2013, p.50). Moreover, it advocates for ideas of affinity and companionship, recognising that we never do things alone, that there is a need to engage with pain and discomfort in order to transform it (Braidotti, 2013, p.50).

This research used an innovative posthuman observations framework that allowed hidden, elusive learning to be seen. The study highlighted the similarities between both participant groups and how this affinity was more important than identity (Haraway, 2017). We argue that learning occurs beyond memory and consciousness, as the elderly people with dementia demonstrated in the music sessions. It appeared that family members and carers were more attached to ideas of identity, to restoring the old 'self' of the person living with dementia. In contrast, the case studies used in this research illustrate how *potentia* disintegrates the ego (narcissism, paranoia, negativity) and installs a positive power.

This intervention provided a fertile ground to challenge engrained ideas about learning and identity. Seemingly, young children are perceived as curious and older adults (especially those with dementia) as in need of reclaiming their identity. The intergenerational sessions demonstrated that these roles can be reversed, and that both groups can learn from and with each other. *Making Bridges with Music* has helped to change negative narratives about dementia. It reveals alternative modes of thinking about the potential for learning that exists for those living with dementia which we will continue to explore in our final chapter.

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Chapter Five: Conclusion

Abstract

In this chapter we present our book as an agent of change. We argue against the dominant use of memory, which traps people with dementia and their families in the past. Instead participatory approaches to learning should be built into all forms of dementia care. We show how our posthumanist perspective has revealed meaningful moments of learning. Rather than being a wasteland for learning, and an absence in lifelong learning agendas, dementia is presented as a site where learning can and should happen as a right. We conclude by arguing that we cannot afford to consign millions of people with dementia and their families to waste. By recognising, fostering and resourcing lifelong learning in dementia a huge contribution to a sustainable planet could be made.

Introduction: “living inside ideas” about dementia

... I learned that culture matters that it's the substructure of beliefs that shape politics, that change begins on the margins and in the shadows and grows toward the center, that the center is a place of arrival and rarely one of real generation, and that even the most foundational stories can be changed. But now I recognise it's not the margins, the place of beginnings, or the center, the place of arrival, but the pervasiveness that matters most.

We live inside ideas.

(Solnit, 2019, p.2-3)

It is Solnit's feminist project to challenge the pervasive patriarchal ideas that shape culture; but with a positive belief that 'even the most foundational stories can be changed'. We argue that these pervasive ideas include the negative positioning of

dementia as always and only a loss; and like Solnit we present this book as an agent of change. Ideas shape practices and the idea of loss simply leaves people with dementia stranded, defined only by the past and confined by it. It is the idea of loss that designs well-meaning dementia living environments with corridors lined with fake shopfronts of a past age: sweet shops and grocers with nothing to buy. It leaves family networks with nothing to hope for but to retrieve a glimpse of a lost self.

We cannot deny that the world of dementia is a harsh one, but in it's rigour it can be transformative as well as traumatic. It can radically change the being of families as well as sufferers:

“When you hear all of the nonsense that is going on about people wanting this and wanting that and the nonsense you get around Christmas and all that sort of thing and I think ‘People think they are having a hard time, but you want to come in here and have a look and see what reality, not reality TV, but see what reality in life really is like you might appreciate what you have got a bit better.’ I feel really strongly about that. It kind of completely changed my life really, but not in a bad way.”

JQ “How has it changed your life then?”

“Just in my outlook really and wanting to do, wanting to do things to help people really.”

(Peter, Stella's husband, interview)

There is energy and resistance here and some abandonment of ego. This comes close to what Braidotti (2013) names as *potentia* and is something we saw across families in *Beyond Words*. It is hard won but in their own ways they counter the

pervasive idea of loss and try to struggle onwards. In this book we argue that lifelong learning could take hold of the potential in both people with dementia and their families and make productive use of it.

The Trap of Memory: “I always remember us”

As previously discussed, memory has been the guiding force in dementia care; down to the ersatz form of memory found on the walls of care homes. What happens if we change our ideas and approach people with dementia as who they are, not as who we remember them to be? They have entered into a different form of engagement with the world and the construction of the human does not accommodate, cannot deal with, this bursting of the bounds of body, time, space. Instead of placing the person with dementia aside as “dead” or “not as they were” we must put the limited category of ‘the human’ aside to make way for something new. In a sense we must become like the responsive music leaders in *Beyond Words* in facilitating and responding to multiple intra-activities.

“The ability to tune in and use your instincts and to kind of evaluate what’s happening in the moment, assess it, adapt it and change.”

(Music Leaders focus group)’

It would be cruel to completely deny the value of memory to family networks. There were many poignant instances where fragile memories were retrieved and held as talismans against loss.

“we didn’t particularly get on through my teenage years, but I always remember her, we always used to have a bit of a laugh and a dance. I always remember us dancing round the room you know Top of the Pops and kind of we used to dance around to that.”

(Marie, Stella's daughter, interview)

However, an insistence on memory can trap family members like Marie in regrets which they struggle to escape: "I think um (voice is broken and tearful) the hardest thing for me is that for years we didn't really talk or we fell out over stupid things." To consign the person with dementia (and their families) only to their memories, even at a very late stage of the disease, seems to deny that people with dementia are alive; but as they *are* alive, they can learn.

Learning in and through Dementia: "finding the treasures"

Rather than constantly trying to steer people with dementia back to the past, their capacity for curiosity needs to be stimulated. Support care workers in *Making Bridges with Music* came to recognise this and carers like Helen in *Beyond Words* already follow it in their practice.

JQ: "I am interested in this word you use 'fluidity' and that there's a lot of movement in a sense in your group (of people with dementia)...again going back to this idea of them teaching you, or everybody, this fluidity do you think that there something in that that we can learn from?"

"Absolutely because that is where the magic happens, you know the point where you maybe start to let go and let them lead is the point where you really start to discover the treasures."

However, "discovering the treasures" of dementia and respecting such leading and learning needs to be more than an individual practice. Participatory approaches to learning need to be built into all forms of dementia care training and the dementia care provided by institutions. This would have to go beyond the norms of lifelong learning and its focus on voice and the human, to recognising the significance of

objects, spaces, bodies and other forms of matter. It would need to abandon any idea of linear progression and outcome to free up moments of 'new worlds' that are transitory but vital.

As has often been argued (see, for example, Freire, 1972, hooks, 1994) learners are the true teachers. The participants in our studies teach the lessons that: bodies can occupy time and space differently, that words are not a necessary part of a claim to validity and they need not be articulated in a learning (or teaching) exchange. It is extremely difficult to shake off humanism as this is what shaped Western thought culturally, socially and through formal education. Moreover, the term posthuman might tend to suggest that the problems faced by humans are over and solved; which is so far from being the case. Nevertheless, humanism has been at the root of many of these problems and in its belief that the human is the arbiter of all things has placed the more-than human world in mortal danger. Posthumanism offers a way of redefining and opening the category human to include and validate our participants and others like them in advanced dementia, who are often seen as waste. We construe them as post verbal, communicating in different ways, not empty and non-verbal'. As Jones and Hoskins (2016) demonstrate in their analysis of a Maori tattoo as a holder of meaning, the primacy of words has not always held in all cultures. There is much to learn from others to free European thinking about what constitutes learning.

In order to recognise that learning takes place in dementia, a new conception of time needs to be employed. Humanism has much invested in the notion of linear time leading to enlightenment. Education grounds its practice in the accumulation of learning over time, leading to the perfected educated person. In contrast. posthumanism sees past, present and future as always entangled and always alive and all forms of matter as always in a state of becoming. People with advanced

dementia have run out of linear time, but they still live in the time of the now (as we all do) and in this time they can learn. These moments of learning time spin and vibrate in ways that are difficult to name but easy to feel. ‘We say ‘now! ‘now! now!’ or we count ‘more! more! more!’ as we feel it bud’ (William James quoted in Burdick, 2016, p. 70). For those that love our participants with dementia, these moments are ineffable and invaluable, even though they are transitory. *Beyond Words* and *Making Bridges with Music* demonstrate that stimulating such creativity and learning amongst people with dementia carries benefits across to their close networks. It can help relieve some of the suffering they have experienced that we charted in Chapter One.

The value of moments: “It’s wonderful”

Both *Beyond Words* and *Making Bridges with Music* showed that rather than looking for tangible outcomes that can be measured, a lifelong learning for dementia needs to work with moments and furthermore needs to see them as precious, not fragments. We are aware that this change of perspective could lead to criticisms that we are making too much of small things; but in a sense this insistence on validating the spark of the moment is at the heart of our argument for lifelong learning in dementia. The focus group with volunteers and apprentices in *Beyond Words* celebrated this new perspective which abandons linearity and measurement:

CB “Are there any benefits to working with post-verbal people?

“It’s wonderful.”

“It’s wonderful?”

“It *is* wonderful.”

“I think because look, there’s no, I’m trying to find the right word for to achieve an outcome. You can go on these like amazing journeys, it’s non-linear if you know what I mean.”

Such “amazing journeys”, led by and in response to, people with dementia are the ideal forms of lifelong learning that we envisage. They cannot be measured by volume or length, but by intensities.

Our research studies demonstrate the value of skilled arts interventions in stimulating such lifelong learning journeys. Our research contributes to the call for increased funding for the arts in fostering wellbeing across all walks of life:

JQ “What do you think the music sessions would give somebody like Stella that other types of activity don’t, or is there no difference?”

“Um well the music does have, I think music will have a different response, effect because obviously there is the sight of people playing, the sight of people listening and joining in and there is obviously the sound of things that will probably bring back memories so it’s kind of unique. Music is a unique thing compared to other things that you might do you can have quizzes and you can have games and this and that but it is not the same I don’t think. It doesn’t attach. It doesn’t integrate with so many senses as music does.”

(Peter, Stella’s husband, interview)

We certainly observed this capacity of music to engage and include. Nevertheless, lifelong learning is not dependent on the arts, but on everyday creativity and openness to potential. As Quinn has demonstrated in her work with marginalised young people (2017), people engage in learning informally everywhere and there is no reason why a dementia care home should be any different. The crucial factor

is that the potential for learning (and teaching) is recognised and followed. Sabeti (2015, p. 213), In her analysis of the group experience of older people who have taken part in a writing course, demonstrates that, contrary to popular belief, they do not use creativity to recapture the past but to focus on 'dwelling in the present'. For people with dementia this seems even more true. Once it is understood that dementia is a space where learning can take place this changes every assumption about how care environments are designed and care is given. *Making Bridges with Music* brought to the fore the similarities between young children and elderly people with dementia. This enabled practitioners and carers to change their practice to make it more open to learning. This shows that dementia care can change when assumptions are challenged.

Dementia Research: “ no one can be in their head”

“So you know you look at people that have got dementia and you think you know: ‘they’re gone’. But you know we don’t know, not even the best experts don’t know exactly what they do know, what they can understand...no-one can be in their head can they?”

(Peter, Stella’s Husband, interview)

Trying to know what a person with dementia thinks sends us spinning. It means that the traditional qualitative nodes of interpretation are even more in doubt than ever. We discussed in Chapter Two that there is a crisis of representation in qualitative research as the ability to understand and represent a knowable person has been fundamentally questioned. Bodies, acts and matter, not thoughts and rationality have become what interest feminist new materialists. This shift is even more necessary in research with people with dementia. As discussed in Chapter Four our innovative posthumanist

framework of observations allowed us to focus on intra-actions and assemblages. This approach helped to decentre the human and any focus on 'self' or any pretence of self-knowledge, and highlighted the potential for learning that exists for people living with dementia, their families and carers.

Posthumanism as an approach to empirical research, is very much in its infancy, but it calls into question and overthrows deep-seated assumptions about who the human is and how s/he learns. As Edwards (2016) suggests it marks the end of previous configurations of lifelong learning. However, posthumanism also offers new tools for understanding which need developing and employing for a reconfigured future. As we have shown, posthumanism allows exploration of learning; when it has gone beyond into another realm where we need to learn how to follow. Posthuman theories are proliferating, but there seem to be limited instances where longitudinal empirical data is used to expand and elucidate those theories. We argue that posthumanism is a vital tool for understanding learning in dementia, but also that people with dementia can add considerably to the development of posthuman understanding and research. They bring the intra-activity and affinity that shape our world into relief and help escape the normalising assumptions of humanism. By exploring encounters with our research participants, we have shown that people with dementia can also teach researchers vital lessons about bodies, materiality, time and meaning.

Dementia: not a wasteland for learning

In simple terms it seems that dementia may not be a wasteland for learning. As this learning seems to add value to difficult lives, it is both hopeful and worth understanding. Our studies have shown glimpses of learning amongst people in very late stages of dementia and the implication is that if it is happening there a potential

for learning exists across the different stages and conditions of dementia. By focusing closely on people with dementia, but seeing them as part of an agentic assemblage, we have been able to identify and explore significant moments of learning in depth. These experiences do not suggest that everyone in late dementia can learn, but they certainly challenge the assumption that they can't.

Our book challenges the limitations of the current lifelong learning policy agenda which focuses mainly on the necessity of constant retraining for employability, and so effectively cancels out people with dementia. *Created out of Mind* has fostered new perspectives on dementia, science and the arts. However, there appear to be no real plans for lifelong learning in dementia, even though this is an area with great potential and tremendous social benefits. The limited training that exists focuses on retention of re-existing skills, not generating new learning. As we have shown, the care of those with dementia, very much centres on memory and on the use of the familiar. Instead we should approach people with dementia as potential 'new beginners' (Biesta, 2015) who can benefit from new forms of learning. The efficacy of the arts in promoting wellbeing is being urged on policy makers, but there is a need to link together educational, care and arts strategies in a much more systematic way. Finally, to enable these moves to take place we need to challenge our assumptions about what it is to be a 'human'. People with dementia provide a valuable lesson about the limitations of that category and posthumanism provides useful tools for the necessary rethinking.

Conclusion: Dementia and a Sustainable Planet

Posthuman thinkers are committed to sustainability, but not in the superficial managerial sense of what Alaimo calls 'sustainable this, sustainable that' (2016) which tends to characterise education institutions' drive to survive. Instead amongst

those such as Alaimo (2016) Barad(2007), Bennett (2010) and Haraway(2016)' who have influenced our research, there is a deep concern to recognise the affinities across all forms of matter and to respect and protect them; whether they be people, minerals or animals. The capacities of all forms of matter must be engaged and that includes the capacity to learn. We cannot afford to confine millions of people with dementia to waste; even the benign waste of the protective care home. Similarly, we cannot abandon their close networks to regret and loss. How we treat our most vulnerable 'kin' (Haraway, 2016) tells us much about our values and our priorities. Thanks to years of cuts in the UK, adult learning overall is hardly sustainable; and people with dementia scarcely figure in the picture. Some might argue that with the crisis in basic dementia care, learning is a luxury that is hardly likely to figure. This is backward not forward thinking and it needs to change. We have presented a posthuman ethics of rights for people with dementia and this includes a right to learning. In this book we have explored and demonstrated the capacities for learning and teaching amongst people in dementia. By recognising, fostering and resourcing lifelong learning in dementia a huge contribution to a sustainable planet could be made.

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