Dichotomising dementia: is there another way?

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Abstract   This article discusses the reduction of the complex experience of dementia to a dichotomised 'tragedy' or 'living well' discourse in contemporary Western society. We explore both discourses, placing them in the context of a successful ageing paradigm, highlighting the complex nature of dementia and the risks associated with the emergence of these arguably competing discourses. Specifically, we explore this dichotomy in the context of societal understandings and responses to dementia. We argue for an acceptance of the fluid nature of the dementia experience, and the importance of an understanding that recognises the multiple realities of dementia necessary for social inclusion to occur. Such an acceptance requires that, rather than defend one position over another, the current discourse on dementia is challenged and problematised so that a more nuanced understanding of dementia may emerge; one that fully accepts the paradoxical nature of this complex condition.

Introduction: a dichotomised view

In Western society, the last 50 years have seen a gradual shift in our understandings of dementia as academic, policy and popular discourses on the condition have evolved (Downs *et al.* 2006). Up until the early 1970s, experiences of symptoms associated with dementia were linked to and categorised by age, for example, Alzheimer's disease, established in 1907, was categorised as an exclusively pre-senile dementia, in contrast to the already existing senile dementia (Fox 1989, Lyman 1989). Holstein (1997) documents the historical move to eliminate the demarcation between these two previously separate conditions so that by the 1970s they were together labelled as the single greatest killer disease in the USA. Over time dementia has come to be used as an umbrella term for a range of symptoms that can occur as a result of the deterioration in brain functioning caused by a variety of conditions, including Alzheimer's disease (World Health Organization 2012). Biomedical approaches continue to dominate understandings of dementia, with an explicit focus on loss of function, decline and death; fuelling what has come to be known as a 'tragedy discourse'. The tragedy discourse also dominates carer experiences and stories (Behuniak 2011, Fontana and Smith 1989, Gillies 2011), and continues to be a primary tool of the media (Bartlett and O'Connor 2010, Johnstone 2013, Van Gorp and Vercruysse 2012). However more recently, a move to challenge the tragedy

discourse has seen the emergence of the 'living well' discourse, where the emphasis has shifted from loss and decline to supporting remaining strengths and recognising enduring personhood.

Dementia is a complex and challenging condition that will be experienced differently depending on one's age, class, gender, other health conditions, life experiences and a plethora of other social differences (Innes 2009, Kitwood 1997). Hulko (2004) talks about the intersectionality of the experience of dementia. This is a useful way to understand that the experience of dementia relates closely to the social differentiation present in society. Dementia means different things to different people depending on their social context but it is also experienced across a spectrum of care and support needs, and thus, rather than understanding it as a dichotomised experience of tragedy or living well it must be understood within wider social constructs and contexts. In the tragedy discourse there has been little room for any alternative experience at any point in a person's journey with dementia and this is also reflected in stereotyping language used about dementia or to describe someone with dementia. Critiques of such language used in discourse about dementia suggest that the themes of animalism (Mc Parland 2014), zombies (Behuniak 2010) and social death (Sweeting and Gilhooley 1997) continue to be perpetuated. Thus, language does more than acknowledge the potential tragedy of living with such a condition; it facilitates the labelling of a person with dementia as 'other' (Goffman 1963, Hughes *et al.* 2006, Kitwood 1997), setting them apart as deviant in some form and different from other members of society. Bruens (2014) suggests that dementia has throughout history been used as a term to identify those considered to be outside normal society, that it remains the most terrifying of conditions, and that a widespread response is to treat those with the condition as though 'they are no longer people' (2014: 84).

The move from a social death (Sweeting and Gilhooly 1997) to a living well discourse (DoH 2009) reflects both a challenge to the previous discourse and a push towards the inclusion of the previously absent voices of people living with dementia (Scottish Dementia Working Group 2016, Swaffer 2011, Taylor 2008). Such developments highlight the possibility of living well with the condition and place an emphasis on social inclusion and positive ongoing life experiences (Dupuis *et al.* 2012). Campaigning organisations are working to shift public perceptions and remove stigma through public awareness drives (Alzheimer Society Canada 2013, Alzheimer Society Ireland 2015, Department of Health [DoH] 2012). It is also interesting to note that the language of policy has shifted with the title of the DoH's (2009) English national dementia strategy 'Living well with dementia', offering a strong indication of a shift in discourse to how we can support, enable and promote living rather than dying with dementia.

In addition, this challenge to the tragedy discourse raises important questions about what we think we know about dementia (Whitehouse and George 2008) and how this impacts on diagnosis, policy, practice, theory and both academic and common sense knowledge. Worldwide dementia policy influencers (Alzheimer's Disease International 2012) have shifted their focus away from loss to supporting strengths, and this is also true of UK policy directives (DOH 2009, 2012, 2015). This can be contextualised within a broader ageing well policy landscape (Walker and Maltby 2012), with an emphasis on individuals taking responsibility for their health. In the media, images of engaged older people participating in sports and leisure abound, and these healthy older people are recognised as being consumers who have time and money to spend. However, there is little in policy or the media that acknowledges the role of socioeconomic factors or power relationships on whether a person is able to participate in this healthy older age agenda.

To shift current perceptions it is essential to provide an alternative image of what it means to live with dementia; one that offers possibility and even hope. However, such an approach also has limitations in that it risks disenfranchising those with complex comorbidities and

extreme cognitive difficulties; that is, those who are most vulnerable and who are living with dementia.

It is against such a backdrop that this article considers the predominately western 'successful ageing' paradigm and its implications for dementia. We discuss the tragedy and living well discourses and the dichotomy between the two, before moving on to argue for the need to move away from a dichotomised approach to one that accepts the complex nature of dementia, with the multiple and myriad experiences that may occur along the trajectory of living with this condition. We argue that efforts to normalise people living with dementia risk further exclusion of the most vulnerable and even division among those affected by this condition, and that the acceptance of a living well agenda as a positive move in the dementia discourse must be problematised.

Ageing paradigms

Successful ageing (Havighurst 1961, Rowe and Kahn 1998) is synonymous with terms including 'active ageing', 'ageing well' and 'healthy ageing' and has at its core an emphasis on individual agency and control, the value of independence and the necessity of avoiding dependence, the value of remaining physically and cognitively active and, ultimately, efforts to deny the deleterious aspects of the ageing process. Lamb (2014) offers a useful discussion on the emergence of and rationale for the successful ageing movement originating in the USA and adopted in other Western countries, including Europe and Australia. This movement has been the subject of much debate among critical gerontologists (Biggs 2004, Calasanti 2003, Holstein and Minkler 2003) who argue that one of the consequences of such a paradigm is discrimination against those who are not in a position to engage with active agency in old age or to be productive in a traditional sense. While it is not within the remit of this article to engage with this debate, it does set the scene for our discussion. Older age is associated with dementia, both in real terms, as the risk of dementia increases with age and conceptually, as it remains a condition that continues to be understood by many as part of the ageing process. Indeed 95 per cent of those living with dementia are over the age of 65 (Alzheimer Society 2014). This article thus focuses on dementia as a condition associated with older age but it is worth noting that it is not an attempt to deny the equally challenging experience of living with an early onset dementia. We argue that the very diagnosis of dementia when one is younger has the potential to conceptually catapult the younger person into the terrain or imagery associated with the most vulnerable old.

Higgs (1995) suggests that in the field of health care, older people are presented with two images of ageing: one of the active, healthy person who works to deny old age (the third ager) and the other who is frail and dependant (the fourth ager). Maintaining good health or 'the will to health' is central to third agers' pursuit of a lifestyle in which they have control over their ageing. Thus autonomy is central to third agers and loss of autonomy defines the fourth age (Higgs *et al.* 2009). Dohmen (2014) argues that 'with impairment and decline considered antonyms of successful ageing, the "fourth age" is automatically deemed "unsuccessful" by means of its proximity to illness and death' (2014: 66), while Pickard (2013), in an interrogation of clinical literature on the discourses of senescence and frailty, links the meaning derived from the third age as an opposition to frailty, with the intention of avoiding it. The linking of frailty with the fourth age is further developed by Higgs and Gilleard (2014) who suggest that although frailty is synonymous with the fourth age (the 'frailing' of the fourth age), the overwhelming fear is of an imagined future incapacity and the dread of 'going into care' with the isolation, reduction of autonomy and othering this is perceived to bring. From the point of

view of those in the third age working to maintain health and lifestyle, the fourth age 'appears as a horrific apparition that dramatises lack in a rather potent way' (West and Glynos 2016: 230).

Greenberg *et al.* (2002) suggest that non-old people manage their terror of this potential future by regarding older people as intrinsically different from them. Branelly (2011) also suggests that younger, healthier people distance themselves from older, incapacitated people, while Jönson (2013) argues that non-old people, using a temporal construction of old age, contrast their future selves as essentially different from old people of today. This crucially, permits the justification of practices, such as substandard care in care homes, that would not be seen as acceptable to non-old people's future old selves. The fourth age, then, is for others: 'the necessarily distant negative horizon that cannot be allowed to intrude upon third age positivity and control', thus it becomes 'a horizon we can only dread' (West and Glynos 2016: 231).

A tragedy discourse

If we accept that the paradigm of successful ageing is established, particularly among Western societies, we then need to interrogate where people with dementia are socially located. Van Dyk (2014: 96) suggests that older people who are dependent on care, or have dementia or other severe chronic conditions are 'as marginalized and stereotyped as ever, probably even more so'; in the context of 'successful ageing' they are the 'failed ones' because they have not worked hard enough to maintain a third age status.

Mc Parland (2014), in her study of the general public's response to dementia, suggests that the stigma attached to dementia is made up of a complex interplay of many jeopardies (Brooker 2003, Hulko 2004) and labels (Hughes *et al.* 2006, Link and Phelan 2001) but it is also associated with existing perceptions of care, feelings of hopelessness or futility, and a profound fear of developing a condition that appears utterly arbitrary and totally beyond the control of the individual or the world of science and medicine. She argues this 'dementiaism' is driven not only by the social location or labelled identity of the person with dementia, but also by the emotional responses of others to this social location and labelling, with the public visualising a potential future that symbolises loss of control, loss of self, living in poor care and being viewed as 'mad'. Bond *et al.* (2004) have also described the denial of practical citizenship to people with dementia due in part to others' (including family members') negative attributions of their remaining ability to choose their preferred lifestyles. This, they claim is stigmatising, exclusionary and ultimately, diminishing for the person with dementia exposed to such responses.

Zeilig (2014) details the myriad of emotionally charged metaphors used to describe or discuss dementia in policy and general discourse; all of which evoke a general sense of calamity and have the power to terrify us and make us feel powerless. She points to the ways in which frequently used metaphors shape our consciousness about dementia, frailty and dependency. Bartlett and O'Connor (2010) argue that society continues to respond to people with dementia in a deeply stigmatising way, viewing them as 'tragic, weak and completely incapable' (2010: 98). In an effort to distance themselves from such a potential future, the public regards the person with dementia as 'other', creating a social and psychological distance between themselves and this terrifying prospect (Deitrich *et al.* 2004, Greenberg *et al.* 2002, Mc Parland 2014, Werner and Davidson 2004). This is exacerbated by the growing public profile of dementia as the disease of the century, with Ballenger (2006) arguing that the efforts to inform and educate the public that dementia is a disease and thus not the responsibility of the person, fail to understand the true nature of stigma, described as 'the amount of anxiety surrounding the

boundary between the normal and the pathological' (Ballenger 2006: 114). The stereotypical picture, among the public, of a person with dementia is of a much older person, living in care and entirely dependent on others for their daily living activities (Mc Parland 2014), closely aligned with the construct of the fourth age as a location without agency or autonomy (Gilleard and Higgs 2010).

The context of these understandings of dementia as a location of frailed, unsuccessful ageing creates the opportunity for society to exclude those affected by the condition, creating different rules, different systems and locations of care and affording others the right to make decisions for people with dementia that they would not consider for their own future selves. In the context of ageing, Baars and Phillipson argue that 'processsses of socialisation often carry cultural messages of familiarity versus strangeness that imply practices of inclusion and rejection' (2014: 16). In the case of dementia, this rejection is often complete, when the person with dementia, now regarded as 'other', moves into care, literally making the transition from one world to another. Care homes have been, and to a great extent still are, regarded as a last resort (Townsend 1962); the place where people with dementia must go when they have moved beyond manageable boundaries in our world. Indeed Gilleard and Higgs (2010) suggest that nursing homes have become as terrifying as the workhouses once were. At their most cognitively impaired and thus most vulnerable, people with dementia are not regarded by the general public as 'of our world', nor considered to be bound by the same rules, nor are their human or citizenship rights respected to the same extent as those without dementia (Graham 2004, Kelly and Innes 2013). In the context of the successful ageing paradigm, those with dementia who are most frail have failed the living well test.

Living well – a positive discourse

A diagnosis of dementia inevitably threatens personal identity, roles and expectations for a person's future, and language such as zombie, patient, disease, sufferer, dementing or demented does little to allay fears about such losses. In a movement to counter the impact of such positioning language and its negative consequences, Kitwood (1997) argued that it was possible, and imperative, to support those with dementia to live meaningful lives and that this could be achieved by supporting their personhood; their unique sense of their personal identity, through interactions that have at their core the goal of meeting the individuals' needs of comfort, attachment, inclusion, occupation, identity and, ultimately, love. Sabat (2001) developed this understanding to encompass notions of enduring selfhood that, although contingent on recognition and support from others (Kelly 2010), enable the person with dementia to live well. Kontos (2005) takes this further by applying the meaning this has for the experiences and delivery of care and support, demonstrating that the conceptual understandings of dementia have a very real impact on lived experiences (Kontos and Naglie 2009). This approach to giving voice to people with dementia has been extended to using creative approaches to present the views and experiences of those living with dementia. Killick (2014) has worked using creative media to challenge the public's fear and helplessness associated with dominant medical conceptualisations of dementia; by using poetry to give voice (Goldsmith 1996) to insights of living with dementia. His work is visionary in that it seeks to de-mystify the experience of living with dementia and to illustrate that living with dementia can also be joyous, humorous or creative. Snyder's work highlights the power of language and extra-linguistic communication via body language, facial expression or vocal tones in impacting on intercommunication. She calls us to regard people with dementia as our teachers: 'we must listen to them as if the well-being of humanity depended on our understanding' (Snyder 2006: 274). This resonates with Post's

(2006: 225) proposal that society must affirm the 'continuing moral status of the deeply forgetful'.

Research on positive approaches to dementia has included cognitive rehabilitation (Clare and Woods 2001), coping strategies used by people with dementia (Clare 2002) and self-management (Toms *et al.* 2015); all part of a body of work countering the nihilism of a tragedy discourse. Genoe *et al.* (2010) discuss the ways in which people with dementia actively work to maintain their personal identity and social roles and describe how family carers use mealtimes to honour the identity and humanness of the person with dementia: emphasising their strengths, respecting their dignity, their uniqueness as individuals and their common bonds as members of a family. Genoe and Dupuis (2011), drawing on Sabat's work, show that experiences of threat and loss in dementia were resisted by adapting and recreating identity through leisure, illustrating the work that people with dementia do themselves to counter the challenges of living with dementia. Although a movement in the right direction towards hearing the voice (Goldsmith 1996) of people with dementia, research into their experiences remains disproportionate, potentially excluding the experiences and voices of those who are most cognitively impaired and most frail. Indeed, Bruens suggests that the subjective experience of people with dementia in formal care settings 'is still very rarely heard' (2014: 92).

The positive or living well discourse has gradually developed in academia and policy but has yet to have a significant impact on public discourse (Bartlett and O'Connor 2010, Bruens 2014, Mc Parland 2014); instead, this discourse remains primarily one of tragedy, as seen in the literature, media representations and personal accounts. Policy ambitions and campaigning organisations are working to move this living well discourse into public awareness in their efforts to remove the stigma reported by people with dementia and their family carers. Recent campaigns (Alzheimer Society Ireland 2015) are using images of people living well with dementia; images of people continuing to participate in 'normal' life, who are articulate and physically able. Highlighting the normality (Baars and Phillipson 2014) of the life of the person with dementia, these campaigns challenge previously established notions of the 'empty shell' or 'living dead'; and offer an alternative image to the dominant stereotypical image of the most vulnerable and frail person with dementia. This living well discourse has, perhaps for the first time, allowed our understanding of dementia to move towards the successful ageing paradigm.

Dichotomising dementia

We have shown that there are two opposing discourses constructing understandings of dementia; the tragedy discourse and the living well discourse. However, we suggest they are neither co-existing successfully, nor offering a happy marriage that might create a discourse that is more reflective of lived reality. Efforts to include the voice of the person with dementia have seen people living with this condition participating in research, presenting at conferences and featuring in campaigns to shift public understandings. In these instances they are often young and well educated, usually, and often of necessity, not living with the most challenging aspects of this condition. Page and Keady (2010) suggest that there remains a tendency to privilege male and middle class voices over poorly educated female ones. There is scant literature on the expressed experiences of people living with dementia in non-Western cultures (Mazaheri *et al.* 2013), and as already stated the argument we present here is grounded in a Western perspective and draws on Western literature. However Mazaheri *et al.* suggest that 'the core experience of people with dementia is to some extent universal, despite differences in cultural and

political contexts and with different religious beliefs or confessions' (Mazaheri *et al.* 2013: 3037).

Perhaps in line with the successful old, those arguably living well or successfully with dementia could in many respects consider themselves still residing in the third age; agents in creating their own future. Thus, it would appear that the positive, living well discourse does not generally include those living with the most severe cognitive and physical challenges; people with dementia who are usually living in institutional care. We suggest that, currently, rather than being viewed as differing aspects of the same experience, these two voices on the discursive continuum of dementia are potentially competing with each other. If we consider some of the earlier arguments, it is perhaps not surprising they have initially emerged in this competitive form.

A further paradox relates to the voices of people living with dementia in the public forum, whether at conferences, via blogs or in campaigning activities. Many do not draw attention to the more frightening potential future they may face; the fourth age. They concentrate their efforts on encouraging society to recognise people with dementia as normal people living with a difficult condition; they are fighting for inclusion and recognition. This is an entirely legitimate and powerful discourse that is intended to move people with dementia out of the shadows and ensure that they are included as full members of society. In the context of ageing, Van Dyk (2014: 14) refers to the fruitless dichotomy of sameness ('they have to be like us') and difference ('they are the others'). We take this further and question whether people with dementia should have to aspire to be the same, as this still potentially positions them as different if their condition progresses to a point where they are unable to articulate their needs or where they require assistance with all their daily living activities. The risk of a tragedy or living well dichotomy is that it divides people with dementia into those who are living well or successfully with dementia and those who are no longer able to maintain society's notion of living well, and are thus living in the shadows.

Offering the opportunity for new ways of living with dementia and the potential for more acceptance is a tantalising possibility but, similar to Van Dyk's (2014) description of the active ageing paradigm, it in fact offers a new set of social expectations. Furthermore, it is an opportunity that is available only to those meeting certain criteria. Critical gerontologists have raised ethical objections to the idea of anti-discrimination and re-valuation based on achievement and outcome. They criticise the attempt to challenge negative stereotypes of old age with the assertion that older people do contribute to society and are thus worthy and valuable (Martinson and Halpern 2011). Based on these criteria, some people living with dementia will no longer be among this group of the valued and worthy. Lamb asks if the Western paradigm of successful ageing comes at:

> The expense of coming to meaningful terms with late-life changes, situations of (inter)dependence, possibilities of frailty, and the condition of human transience? – setting up for 'failure' embarrassment, or loss of social personhood those who face inevitable bodily or cognitive impairments and impending mortality. (Lamb 2014: 42)

In a thoughtful interrogation of others' perceptions of her mother, living with dementia in a care home, Taylor (2008) also challenges notions of social death (Sweeting and Gilhooly 1997) and the denial of recognition as friend and fellow human being of a person with dementia.

A shadow reality, on the edge of society, continues to be the daily experience of many people living at the most extreme end of dementia. Our concern is how to remember and respect this most vulnerable group of people in the context of the new imagery associated with living

well or successfully with dementia. While the newly visible group of people living well with dementia strive to convince society that they are part of its normality, the more vulnerable group of people living with advanced dementia continue to epitomise deviance, differentness or 'otherness'. Baars and Phillipson suggest that 'normality is an elusive concept that invariably serves specific interests' (2014: 11), and struggles on the part of people with dementia to be accepted as part of normality may prove equally elusive. Moving society towards a respectful acceptance and inclusion of the most vulnerable living with dementia is a difficult endeavour, for this group continue to represent that most primal, transcendental fear: 'loss of self'. In our hyper-cognitive society (Post 1995), loss of cognitive ability is closely aligned to assumptions of loss of self, and the physical frailty and diminishing control over bodily functions that often accompany it act to further enhance the fear of this condition. The fear related to dementia is primarily of where we might be socially located as a result of the condition, and that location is within the fourth age, stripped of choice, autonomy and self-expression (Gilleard and Higgs 2010); no longer viewed as a 'real' or 'complete' person.

At a philosophical level dementia arguably represents the human struggle with life and death and our lack of control over these states. Bavidge (2006) has challenged our views of life, death and dying, asking why we view the cognitive impairments that may occur as we grow older as pathological, yet not view the cognitive impairments associated with childhood and adolescence as pathological. A child who does not speak but simply smiles and watches the world go by, responding to touch, sound and smell, is regarded with joy and valued by virtue of their presence in the world. A person with dementia who does the same is regarded with dismay and, if viewed as no longer contributing to society in a meaningful way, is not valued or at least not valued equally.

If we fail to challenge and redress the current dichotomy of these discourses, the risk is that, rather than changing the script around dementia we have simply shifted the boundaries so that some people will live with acknowledged difficulties, accepted and, it is hoped, valued in society for longer periods of time, but some will not. We risk a discourse that urges those living with dementia to fight to continue to meet society's definition of a life that is normal and has value, rather than challenging the very definitions of normality and value. For some, the progression of the condition may mean they never reach what has been described as the fourth age before death. However for many, dependence and potentially care-home life will become a reality at some point in the trajectory of their condition. Unless we challenge societal responses to this life, then the best that can be hoped for with the living well discourse is to delay this frailing life. Furthermore, the group of people living at an earlier point in their dementia and struggling to resist or even deny the most frightening potential of their condition are perhaps the most likely to 'other' this vulnerable group in their efforts to create a social and psychological distance from their potential future. Such a discourse, in effect, means that while some progress has been made in that some of the people living with dementia will be better included in our society for longer, others inevitably no longer will be.

Conclusion

Dementia is a condition that society has been unable to overcome. It is also a condition primarily associated with ageing and Baars and Phillipson suggest that 'modern cultures of ageing often have difficulty acknowledging and dignifying limitations that cannot be overcome but must be successfully integrated in ways of living' (2014: 26). It could be argued that society continues to deny the multiple and complex realities of dementia, albeit in a new form; the living well discourse. Efforts to shift policy and public perceptions through a positive

discourse may potentially contribute to the further exclusion of the most vulnerable living with dementia. Rather than this discourse addressing the cultural and societal responses to an undeniably challenging condition, it may instead perpetuate divisive public perceptions and indeed create division among people with dementia themselves. We argue that discourse should recognise the myriad of experiences and the inherent complexity of living and dying with dementia. The notion of living well with dementia has been a necessary response to counter the previous tragedy discourse. However, it could be argued that in many ways it is just as discriminatory, placing new social expectations and criteria on those living with dementia. We argue that it is time to challenge the idea of living well, particularly in the context of active ageing; to challenge the notion of normality and of value in the ongoing dementia discourse. Baars and Phillipson (2014: 26) suggest that 'celebrating ageing as a vital part of life implies recognition of the potentials *and* limitations, the pleasurings *and* sufferings, the continuing vitality, competence *and* vulnerability of ageing'. Applying such a celebration to dementia would mean accepting that the discourses of living well and tragedy are equally compelling aspects of living with dementia, and that the denial of one or the other is disingenuous. Dementia discourse must acknowledge the limitations associated with this condition, while discovering the remaining pleasures. At the core of both discourses exist some of the truths inherent to experiences of dementia. Unpicking and facing other truths and realities; both the frightening and the joyous, the painful and the liberating, offers the opportunity to produce a future discourse that would more accurately reflect and support the multiple realities of dementia, reduce the risk of marginalisation and create the opportunity for social inclusion.

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