



Article

Young onset dementia: The impact of emergent age-based factors upon personhood

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Abstract

This paper evaluates how emergent age-based factors may impact upon the experience of dementia. A review of selected literature is undertaken to explore how personhood has been conceptualised in relation to dementia. It is then highlighted that very little literature explicitly addresses personhood with reference to young onset dementia. Young onset dementia is defined, and evaluation is then undertaken of the distinctive age-based factors that might shape the experience of the condition. It is noted that whilst there are separate literatures on both personhood and young onset dementia, there appears to be little endeavour to draw these two strands of thought together. The distinctive factors that shape young onset dementia suggest that a more heterogeneous perspective should be developed that accounts more appropriately for how personal characteristics shape the lived experience of dementia. The paper concludes that further research should be undertaken that has an explicit focus on personhood and young onset dementia.

2 **Keyword**



3 **Introduction**

This paper considers the importance of understanding young onset dementia whilst taking into account the concept 'personhood'. It is highlighted that 'dementia has traditionally been

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understood as a biomedical phenomena, a disease with a trajectory of irrevocable decline resulting primarily from neurodegenerative changes' (O'Connor et al., 2007, p. 112). Whilst a biological/medical perspective of dementia may still strongly shape social perceptions of the condition, this discourse has been challenged by authors who argue that psychosocial factors will also impact upon the nature of the condition. This challenge states that dementia is to some extent socially constructed with a plethora of psychological, situational and social factors shaping experience.

However, the particular requirements of people with young onset dementia also need consideration. There is a limited but growing body of literature on young onset dementia that highlights that aspects of the condition may be experienced differently by younger people. How this literature relates to conceptualisations of personhood demands close consideration, and the importance of considering young onset dementia from this perspective also requires evaluation.

Personhood and dementia

A number of different terms are used within research that sets out to orient dementia studies away from a biomedical perspective to incorporate the experiential perspective of the person with dementia. Terms such as 'self', 'selfhood', 'self-identity' and 'personhood' are deployed in this literature. Each of these terms is difficult to define precisely and they are likely to appeal depending on different aspects of subjective/social experience. However, it can be argued that regardless of the specific terminology, the overriding intention (whether the stated referent is the self, selfhood, self-identity or personhood) is to underscore the socially-constituted personal experience of dementia. The aim for authors operating within this framework is to conceptualise the person with dementia as an agent whose personal beliefs and actions, as well as their social relations, transcend to some extent the biological basis of the condition. Whilst the different orientation of these terms is acknowledged, the cord of consistency running through this literature is the focus on the person with the experiential perspective of dementia (socially realised). This paper will tend to deploy the term 'personhood', but the intention is to capture the essence of papers that focus on a conceptualisation of the lived experience of the person with dementia, whether the purported referent is the self, self-identity, selfhood, identity or personhood.

In her study of early stage Alzheimer's disease, Clare (2004) highlights that there is extensive literature that presents 'lack of awareness' as a biological symptom of the condition. From a medical perspective, awareness is perceived as having clear correlations with brain function, and is measured by a clinician as being either intact or absent within the context of a medical consultation (Clare, 2004, p. 1018). This perspective marginalises the psychosocial factors that should also shape an understanding of awareness. The onset of an illness such as Alzheimer's disease presents a threat to the self, with the expectation that it will be increasingly difficult to carry out conventional roles and tasks. The self is not an isolated biologically-constituted unit, and is socially defined. The threats to the self resulting from a decline in competence have social foundations: the self is defined and constructed through social relations and interactions with others. The positioning of the person with Alzheimer's disease within these social relations will affect their experience of the condition with constructive interactions reinforcing a positive sense of self, whilst unhelpful responses may be detrimental. In the endeavour to present the self in a fashion that will limit altered social responses from others, the person with Alzheimer's disease may hide memory lapses or

may opt to proffer a detailed account of their experience so that others are fully informed. 'The implication is that the individual will make choices about the presentation of self that reflect attempts to deal adaptively with the perceived threats to self and prevent unhelpful or uncooperative responses from others' (Clare, 2004, p. 1018). The person with Alzheimer's disease therefore actively shapes others' perceptions of their awareness through their aim to define their socially-situated self: awareness does not therefore have a simple correlation with the biological effects of the condition.

O'Connor et al. (2007) underscore that dementia has been understood as a biomedical phenomenon; that is, as a terminal condition defined by neurodegenerative changes. However, they recognise that the behaviour and quality of life of people with dementia is not only determined by neurological factors, 'but also by their personal histories, their interactions with others, and by how they are perceived within their social contexts' (O'Connor et al., 2007, p. 122). Building upon this insight, a conceptual framework is proposed that aims to prompt the research agenda in a direction that can more comprehensively understand the experience of dementia. Following Clare, it is recognised that subjective experience is crucial for understanding dementia. It is then suggested that the interactional environment in which subjective experience is framed should be a quasi-autonomous locus of analysis. 'When taking the position that personhood is constructed through ones' interactions with one's world, a focus on the living environment becomes critically important for conceptualizing and understanding personhood' (O'Connor et al., 2007, p. 127). The authors cite the work of Kitwood (1990) whose term 'malignant social psychology' highlighted how treatment by others could have deleterious consequences for the person with dementia. This aspect of the interactional context is developed to consider the influences of the physical environment. The interactional environment is not only comprised of other people but also has physical dimensions that will contextualise and frame experience. It is highlighted that physical space and activities should be considered part of the interactional domain (O'Connell et al., 2007, p. 129). The third component of the conceptual framework is the socio-cultural context. This suggests that the experience of dementia cannot be adequately understood through a lens that simply sees the person with dementia interacting with their immediate environment. The interactional domain will be influenced by broader social and cultural conditions; therefore, these conditions will also have an impact upon personhood. The socio-cultural context must be recognised in research 'to move beyond the immediacy of personal and interactional experiences to identify, for example, the ways in which health policies, institutional cultures and practices, and socio-cultural norms and values shape the experience of dementia and support or impede the implementation of personhood approaches to dementia' (O'Connor et al., 2007, p. 131).

Recognition of socio-cultural contexts demonstrates that a person's social location or positioning will frame the intersection between lived experience and its situational domain. People will not engage with environmental settings from the same social vantage point. It is therefore important to recognise the different social and cultural backgrounds of people with dementia and how factors such as race, ethnicity, socio-economic status, gender and sexual identity will to some extent contextualise the dementia experience (Connor et al., 2007, p. 131). In addition, the social world does not present an aggregate of uniform and undifferentiated interactional settings; aspects of broader organisational/institutional contexts (such as resources, policies and procedures, the emergent value structures of professions) will impact upon the nature of these interactional settings. It is important to

recognise that the socio-cultural environment does not have material properties, but also ideational or discursive dimensions. Societal discourses can greatly shape the experience of dementia, with accepted definitions being drawn upon in interactional settings. For example, the prevailing biomedical perspective may strongly construct the dementia experience as 'suggesting that understanding dementia as a deteriorating disease sets expectations and responses that help shape personal experiences and interpersonal responses in particular ways' (O'Connor et al., 2007, p. 132). Negative language and representations may shape the experience of a health condition such as dementia, and accordingly there may be efforts to provide some counterbalance to these representations. The UK's Dementia Strategy (2007) states that there is a good life to be lived with dementia following diagnosis, and this sets out to promote 'living well' rather than simply dealing with a terminal and degenerative condition.

When endeavouring to understand the experience of dementia, we therefore have to consider different but interrelated dimensions of the social world. Biological explanations are insufficient but neither can subjective experiences be abstracted from interactional or socio-cultural settings. Furthermore, the biological impacts of the condition should not be marginalised, but integrated into a biopsychosocial approach that recognises the impacts of biological, psychological/subjective and socio-cultural elements of the world (Sabat, Johnson, Swarbrick & Keady, 2011, p. 286).

The aforementioned perspectives indicate how effective dementia research can be undertaken via a more rounded conceptualisation of the factors that shape the experience of dementia. However, this awareness also has direct applicability to the delivery of care of people with dementia. Person-centred care is intended to provide holistic care for the patient rather than simply treating a medical condition; the needs of the patient are paramount rather than the requirements of the service or staff. Edvardsson, Featherstonhough and Nay (2010) highlight that key factors of care such as knowing the person, a welcoming family, providing meaning, and a personalised environment can help to promote a continuation of self and normality for the person with dementia. The aim is not just the reduction of unwanted medical or behavioural phenomena but is judged more by existential dimensions. Even as the impacts of dementia threaten the self:

Care staff can apply person-centred care to support the life previously experienced as normal for the person with dementia and their family and their existential experiences of being a whole person rather than being reduced to a patient, a disease or a task' (Edvardsson et al., 2010, p. 2616).

Therefore, the concern to understand the perspective of the person with dementia via social scientific theory and research can contribute to the provision of care through the recognition of the importance of subjective experience, interactional settings and positive cultural contexts.

Person-centred care enables the person with dementia to be addressed as a whole person rather than simply as someone with biologic personhood (Buron, 2008, p. 324), that is, someone whose care is only addressed at the level of physiological need. Sabat et al. (2011) advance the idea that an appropriate conception of the self can help to resist discourses that may illegitimately circumscribe the breadth of the person with dementia's experience. Social constructionist theory is explored with reference to selfhood: it is stated that under this model Self 1 refers to the experience of being the same person from moment to moment, whilst Self 2 consists of one's mental and physical attributes past and present

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(Sabat et al., 2010, p. 287). A diagnosis of dementia would relate to Self 2 and the related dysfunctions associated with the condition. Despite having a range of Self 2 attributes, the person may be viewed exclusively as a person 'with dementia'. The difficulty is therefore that skewed social responses to a Self 2 attribute compound any frustrations and difficulties related to the experience of dementia. However, social constructionism also highlights that we have a range of social personae, known as Self 3 attributes.

For example, among one's social personae might be 'romantic spouse', 'demanding professional', 'loyal friend', 'loving, devoted parent'. One's behaviour patterns as a demanding professional are quite different from one's behaviour patterns as a loving, devoted parent. (Sabat et al., 2010, p. 290).

A rounded perspective of the socially-constructed human self means that Self 3 in all its varieties should not become subsumed under Self 2 attributes. Positive narratives can help to resist discourses that would contribute to a situation in which negative Self 2 attributes are the defining human qualities.

The aforementioned views demonstrate the importance of capturing the experiential perspective of dementia in such a way that a rounded conceptualisation of the person with dementia is adequately represented. They present the varying aspects of psychological and social conditions that are an intrinsic feature of the experience of dementia. Whether it is the self, identity or personhood that is being considered, this cannot be appropriately understood without grasping the intersecting impacts of biology, psychology and social conditions. Appeals to personhood also highlight how this rounded viewpoint relates to person-centred care and the resistance of narratives that may have negative impacts upon the experience of dementia.

Young onset dementia: an absence of attention to personhood

The examples above demonstrate that there is a desire to assert the importance of personhood with regard to dementia. Whilst the biomedical perspective may still strongly shape professional and social perceptions of dementia, there is a body of literature that resists this discourse and promotes different aspects of the dementia experience. Subjective experience and situational/social conditions will impact upon the person with dementia and have distinctive influences upon manifestations of the condition. However, whilst this demonstrates an overall concern for the experiences of the person with dementia, it can be argued that the literature does not fully account for the variety of social vantage points from which experiences of dementia are constructed. For example, it is highlighted that there has 'been little attention devoted to examining the ways in which identity intersects with class, race, gender and ethnicity in constructing the subjective experience' (O'Connor et al., 2007, p. 126).

A further characteristic that may shape the experience of dementia is age. There is very little literature that considers both personhood and young onset dementia. A systematic review paper considers the impact of dementia on self and identity (Caddell & Clare, 2009) but no mention is made of any distinctive factors that young onset dementia presents which might have an impact upon the person with the condition. A paper that does directly consider personhood and young onset dementia recognises that younger people are an overlooked population for research, policy and practice attention (Harris & Keady, 2009, p. 437). Whilst this may be the case, there are a growing number of studies on young

onset dementia and, as demonstrated above, literature has considered dementia in general terms in relation to the self and identity. However, there currently appears to be very little endeavour to draw these two strands of thought together, that is, in consideration of the particular aspects of self and identity that impact upon the experience of young onset dementia. This paper now considers studies on young onset dementia and evaluates the potential benefits of recognising the distinctive aspects of the condition that might prompt more refined conceptualisations of personhood in relation to dementia.

Young onset dementia: defined

Young onset dementia is defined in the UK as anyone diagnosed with dementia under the age of 65 years. The terms 'early onset dementia' and 'working age dementia' are synonymous with young onset dementia. There are more than 16,000 younger people with dementia in the UK; however, this is likely to be an underestimate and the actual figure could be up to three times higher (Alzheimer's Society, 2010, p. 1).

Whilst these numbers demonstrate why young onset dementia is a growing concern for researchers, clinicians and policy-makers, young onset dementia raises additional considerations as a result of its 'non-normative' nature. The prevalence rates for dementia are significantly lower for younger adults: 1 in 1400 people aged 40–64 years have the condition, compared with 1 in 25 people for the age range 70–79 years, and 1 in 6 people for those aged 80 years and over (Alzheimer's Society, 2011).

The impact of young onset dementia

Whilst young onset dementia is under-researched, there is a growing body of literature that highlights the distinctive impacts that dementia has upon younger adults and their families. It is argued that the non-normative nature of the condition may mean that dementia is experienced differently by people with young onset dementia in comparison with people with older onset dementia. 'Dementia is socially defined as an old person's disease. And although the definition of dementia has changed over time, its correlation with the aging process has not' (Harris, 2004, p. 17). Definitions themselves will have an impact upon the person with dementia. A distinction can be drawn between 'natural' and 'interactive' kinds of phenomena. With the former kind, natural objects (such as trees, mountains and chairs) more or less exist independently of social definitions but with the latter kind, personal and social definitions actively shape a person's experience. Interactive kinds of objects are efficacious when they are known by people and articulated via institutions, they 'change the ways in which individuals experience themselves – and may even lead people to evolve their feelings and behaviour in part because they are so classified' (Hacking, 1999, p. 104). Definitions of dementia are therefore likely to intersect with other age-related definitions. The definition of dementia, as associated with the ageing process, may thus have varying impacts according to the age that the condition is diagnosed, with the non-normative nature of young onset dementia having substantial impact upon the person with the condition. Furthermore, the definition, 'young onset dementia' may have independent effects, with the availability of specialist age-specific services reinforcing this definition and the absence of such services potentially attenuating the effects of this age-related definition.

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The fact that dementia is defined as an older person's disease may therefore raise distinctive experiential issues for the younger person with dementia. Harvey (1998) states that young onset dementia can be considered from two perspectives: 'medical and scientific research findings relating to the disease; and that of the organisation of the health and social services providing care for these patients and their families' (Harvey, 1998, p. 11). This perspective shows how young onset dementia has been both biologically and socially constructed. From the medical/scientific perspective there are competing views on the biological underpinnings of dementia. For example, according to some medical research Alzheimer's disease is viewed as a unitary condition whilst in other research it is viewed as a condition that can be defined differentially as there are differences in the neurological manifestations of the condition according to the age of onset. With regard to the latter view it is proposed that Type 1 Alzheimer's disease would refer to old onset disease with Type 2 Alzheimer's disease referring to early onset (Harvey, 1998, p. 12).

The *International Classification of Diseases 10* (ICD-10) (World Health Organization (WHO), 1993) recognises this ambiguity and states that the distinction between Alzheimer's disease with early onset and Alzheimer's disease with late onset is 'controversial' (WHO, 1993, p. 48). However, they do make this distinction in the classification and suggest that at least one of the following requirements must be met for Alzheimer's disease with early onset:

- (a) evidence of a relatively rapid onset and progression;
- (b) in addition to memory impairment, there is aphasia (amnesic or sensory), agraphia, alexia, acalculia, or apraxia (indicating the presence of temporal, parietal and/or frontal lobe involvement) (WHO, 1993, p. 48).

However, no distinction with regard to age is offered for other types of dementia, such as vascular dementia. It should also be noted that the *Diagnostic statistical manual of mental disorders IV* (DSM-IV) (American Psychiatric Association, 2000) states that the subtypes 'Alzheimer's disease with early onset', and 'Alzheimer's disease with late onset' are based solely on whether the dementia was diagnosed at age 65 or under for early onset, and over age 65 years for late onset. The DSM-IV also states that: 'The diagnostic code depends entirely on the presence or absence of a clinically significant behavioural disturbance and not whether the dementia is of early versus late onset' (American Psychiatric Association, 2000, p. 155)

This shows that, whilst the biomedical model of dementia might be resisted and supplemented by a perspective on the psychological and social aspects of the condition, recognition of the distinctive impacts of the biological foundations of the condition, and how these biological foundations are classified, should not be entirely overlooked.

With reference to the organisation of health and social services, Harvey (1998) highlights how the historical development of services has shaped the experience of dementia with the separation of services into general psychiatry and old age psychiatry, the demarcation between these services for the patient being set at 65 years:

Old Age Psychiatrists receive specialist training, and have considerable experience in the investigation and care of people with dementia, but often inflexibility in the organisation of services means that people under 65 years with dementia are excluded from the Old Age Psychiatry services' (Harvey, 1998, p. 15).

Whilst there are increasing numbers of specialist young onset dementia services, the traditional separation of general psychiatry and old age psychiatry is still likely impact upon the experience of services for younger people with dementia, with these services configured to address the members of the population where prevalence is greatest. This contributes to a situation under which many younger people fall though the net of health and social services (Royal College of Psychiatrists and Alzheimer's Society, 2006, p. 5).

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Many dementia care services have a minimum age requirement of 65, and are not available to younger people. Where services are open to younger users, these may not be appropriate to their needs. Younger people often feel that they are made to 'fit in' to a service, rather than the service fitting their needs (Alzheimer's Society, 2010, p. 2).

With regard to the social aspects of dementia that may impact upon younger people, Svanberg, Spector and Stott (2010) undertake a literature review of the impact of young onset dementia on the family and state that 'the needs of younger people with dementia and their families may be different' (Svanberg et al., 2010, p. 1). Whilst they include 26 papers in their review they point out that very few papers take into account subjective experiences, with only two studies aiming to speak directly to the younger person with dementia (Svanberg et al., 2010, p. 11). One study that does aim to elicit the views of people with young onset dementia (Beattie, Daker-White, Gilliard & Means, 2004) found that age was a key theme affecting the experience of the condition. Respondents in this study stated that age-appropriate services were required, as developing social contacts with younger people with memory problems was a positive experience. On the other hand, care offered in older person's services was viewed negatively and there was a sense that the interests of younger people and older people may not always be complementary (Beattie et al., 2004, p. 364).

A review paper that considers the subjective experiences of younger people with dementia (Roach, Keady, Bee & Hope, 2008) highlights that factors relating to employment and the family are likely to present distinctive challenges. For example, the financial effects may be felt acutely as 'the younger person may be at the height of their careers, saving for children's university education, and have significant financial obligations such as mortgages and other credit repayments' (Roach et al., 2008, p. 168). In addition, the impact of young onset dementia is likely to have different effects upon the family and there is a greater chance that the person with the condition will have dependent children. These interrelationships may mean that there is greater need for restructuring of roles across the family which can also be a source of distress. For example, 'young children may be particularly affected by changes in role and these instances are more likely to happen in a family experiencing young onset dementia' (Roach et al., 2008, p. 170). It is also highlighted that these difficulties can have an isolating effect upon the whole family.

A further factor that may impact upon the younger person with dementia links the physical aspects of the condition with its social manifestations. Younger people with dementia are 'more likely to be in good physical health, be physically active and are more likely to be drivers' (Freyne, Kidd, Coen & Lawler, 1999, p. 784). This could mean that reductions in mental functioning are felt more acutely, with losses of outlets such as driving impinging upon the person's independence. High levels of physical functioning could also have impacts upon care management, with carers finding it harder to cope if the condition engenders behavioural problems.

A study that does set out directly to consider selfhood in young onset dementia (Harris & Keady, 2008) found emergent themes relating to the identity profile of the person with dementia:

Integral parts of selfhood, components that comprise anyone's daily sense of self, are affected by this diagnosis from one's identity as a worker, family member, sexual and social being and as an individual engaged in living (Harris & Keady, 2008, p. 442).

The fact that these changes occur in the prime of their lives compounds the stress already conferred upon the individual and their family.

Towards a conceptualisation of personhood and young onset dementia

This brief review of selected literature strongly indicates that dementia may be experienced differently by a younger person when compared with an older person. Whilst the symptomatic distinctions in relation to age may be controversial, the broad range of differences in experiential outcomes for younger people suggests that the distinction is much more palpable in psychosocial terms. This further demonstrates that the condition should not just be viewed as a biomedical condition alone, as different personal and social circumstances will shape the experience of the condition – in this case, the age at which the dementia develops or is diagnosed. However, whilst loss 'of selfhood and self-esteem is an often-mentioned and poignant theme when reviewing the literature of early-onset dementia' (Roach et al., 2010, p. 170), very little attention is paid to how personhood may be constructed at different ages. It is not just the loss of personhood that is crucial but also how the self/identity is constructed at each stage of the condition. An excessive focus on loss of personhood could be argued to differ little from the biomedical perspectives that focus on degenerative aspects of neurological decline.

Literature on personhood highlights why it is crucial to conceptualise the lived experience of dementia from the perspective of the person with the condition. Moreover, literature on young onset dementia raises awareness that research and policy should be attuned to the distinctive age-based characteristics of the condition. However, there is a disjuncture between these two strands of thought, with very little literature endeavouring to develop conceptualisation of personhood in relation to young onset dementia. Studies have tended to view dementia as a generic category with regard to personhood, and it has been demonstrated that they also fail to address other characteristics such as class, gender and ethnicity (O'Connor et al., 2010, p. 206). Whilst it is important to take into account all factors when endeavouring to devise a rounded conceptualisation of personhood, it can be strongly argued that age demonstrates distinctive emergent impacts upon the person with dementia. This means that research could set out to develop notions of personhood in relation to dementia that are more accommodating of these age-related factors, and young onset dementia in particular. An atypical paper (Harris & Keady, 2008) that does explicitly attempt to conceptualise selfhood in relation to young onset dementia demonstrates the importance of age-based factors in understanding experience.

It is possible that, in its nascent state, research relating to personhood and dementia has not yet progressed to consider how such categories might vary according to personal circumstances. According to this view, resistance to the potent biomedical model of dementia requires a coherent perspective of socially-constructed personhood: fracturing this view could potentially generate a less robust means by which alternative

conceptualisations of dementia are presented. However, it can be argued that a failure to fully acknowledge the variety of experience encountered by the person with dementia, and how these experiences are socially structured across the population, means that an excessively homogenous view of dementia is presented. The intention of literature on the social construction of personhood is to demonstrate how social conditions may present difficulties and barriers for the person with dementia rather than these barriers simply being an outcome of the biological basis of their condition. But presenting a view of personhood that is inadequately conceptualised with regard to differences within the population of people with dementia merely underscores the differences between those with the condition and those without the condition.

As has been highlighted in this paper, situational and social factors impinge substantially upon the person with dementia and their self/identity. Meanwhile the literature on young onset dementia highlights that there are likely to be structured differences between the situational and social factors shaping the experience of young onset dementia and older onset dementia respectively. It therefore seems reasonable to propose that the social construction of personhood may take different forms with regard to young onset dementia.

Conceptualisations of personhood and dementia can thus be considered via the perspective of young onset dementia demonstrated in research. Clare's study on awareness (2003) shows that the person with dementia, in the endeavour to avoid social judgements and labels, may hide aspects of their condition. The non-normative nature of young onset dementia, being socially defined as an old person's disease, may compound anxieties around social judgements. Furthermore, the impact that young onset dementia may have on the family, including emotional difficulties experienced by children, may place extra pressure on the person with dementia to conceal the symptoms of the condition. Social pressures and situational contexts will therefore have different impacts depending on the age at which the condition is diagnosed. As a corollary, these pressures and contexts will affect lived experience, personhood and the presentation of the self to others.

This links with O'Connor et al.'s endeavour to develop a research agenda for personhood in dementia care. The authors acknowledge that different personal characteristics will intersect with identity but do not make any explicit reference to age. However, the three key domains that they highlight (subjective experience, the interactional environment and socio-cultural context) are likely to intersect with emergent age-based factors. It is recognised that subjective experiences are shaped by the context of personal relationships and that people are likely to have different relationships at different stages of the life-course. The different kinds of status that a person has will also impact upon the interactional environment, for example, the role of working parent will to some extent shape the person's immediate context and a loss of this role will amend this context accordingly. With reference to Sabat et al. (2010), the younger person with dementia may have a different range of Self 3 attributes in comparison with older people with dementia: these will not just be linked with work and family but could be related to a range of interests and social connections. These various Self 3 attributes could potentially be used to resist being excessively defined by the Self 2 attribute of the diagnosis: however, it is also possible that a loss of a role or skills (relating to employment or a key hobby) could render the application of a Self 2 attribute even more difficult to accept. Recognition of the distinctive nature of young onset dementia can help to orient discourse towards greater appreciation of Self 3 attributes that underpin lived experience, rather than viewing dementia as a monolithic Self 2 attribute.

With regard to care, it has been highlighted that age-appropriate services are favoured by people with young onset dementia but that the separation of general psychiatry from old age psychiatry means that such services are 'specialist' rather than embedded into regular organisational structures. An interactional environment may be supportive if people with young onset dementia can interact with people of a similar age but being placed in a physical environment that caters predominantly for older people could have a negative impact upon the younger person. Alternatively, being treated in a specialist service for young people could also compound feelings of 'difference' generated by the non-normative nature of the condition. With regard to the socio-cultural domain, it was demonstrated that experiences could not be abstracted from this broader context and that a person's position within this context would shape experience. Age is one factor that will intersect with the socio-cultural domain. Social discourses associate dementia with old age: whilst negative discourses on dementia are likely to impact upon all people with the condition regardless of their personal characteristics, certain characteristics may generate a greater sense of stigma. To some extent, social perceptions link physical/mental decline and ill-health with old age. Therefore, when a condition such as dementia is developed at a young age, this confounds notions that decline and old age should have a neat correlation. This creates a context such that the young person with dementia may find it hard to find other people that understand their condition (Alzheimer's Society, 2010, p. 3). This may make it harder for the young person to access information, support and services. Therefore, positive discourses that challenge perspectives which focus excessively on degeneration and the terminal nature of dementia may require additional reinforcement so that those who develop the condition at a relatively young age receive appropriate support.

The requirement to provide person-centred care highlighted by Edvardsson et al. (2008) also relates to the requirement to develop a conceptualisation of personhood that adequately accounts for the distinctive nature of young onset dementia. When providing services for the person with dementia it is important to take into account their subjective experience, interactional environment and also any additional socio-cultural factors. Failing to consider how emergent age-based factors intersect with these domains will limit the extent to which care can be person-centred. Treating the whole person and providing continuity in their life requires an awareness of the specific features of their life and experience. A homogenous perspective on dementia and personhood does not fully support this approach: therefore, a more rounded conceptualisation of personhood is required that is more complementary to person-centred care.

Conclusion

Evaluation of literature on personhood and dementia demonstrates that it is vital to recognise the person with dementia's perspective when trying to understand the condition. This endeavour offers a crucial means by which research, policies and practice can be tailored to represent the person with dementia in holistic personal and social terms. This approach resists merely viewing the person through the lens of the biomedical perspective which tends to reduce the person to the symptoms of their condition.

The fact that an adequate conceptualisation of personhood and dementia is so crucial to an understanding of the condition means that it should be developed to capture the lived experience of dementia as closely as possible. There is currently very little literature that considers personhood with reference to young onset dementia. This appears to be something

of an oversight that should be addressed in future research. This paper has acknowledged that personhood has tended to be viewed in homogenous terms with regard to dementia. Whilst a multiplicity of factors are crucial for understanding a person with dementia's experience, this paper argues that age is a key factor that requires particular consideration. Literature on young onset dementia demonstrates the particular emergent age-based factors that are likely to shape experience of the condition. It therefore seems likely that these factors will make a significant impact upon personhood. An atypical paper that addresses both young onset dementia and personhood (Keady & Harris, 2008) demonstrated that key themes shape the experience of the younger adult with dementia. Greater research focus on personhood and young onset dementia can help to expand upon these themes, and develop them in more depth.

The move to a focus on young onset dementia and personhood does not mean that more general approaches to personhood should be eschewed. Rather, it is asserted that these broader conceptualisations of personhood can be complemented by more specific considerations of the particular circumstances and characteristics of people with dementia. This should not lead to a confused and fragmentary approach but to a more effective and empirically applicable perspective on the experience of dementia. The current presentation of dementia and personhood in fairly generic terms tends to present a homogenous view of dementia that might underscore the difference between people with dementia and people without the condition. Acknowledging the variations of perspective of people with dementia enables a more person-centred view that accounts for diversity of perspectives and experiences.

Furthermore the promotion of a stronger conceptualisation of young onset dementia and personhood does not mean that an essentialist view of young onset dementia is being promulgated. There may be substantial differences within, and between, various groups in society including those defined by age. It must be recognised that a person in their 70s could have dependent children and still be in employment whilst a person in their 50s could have adult children and be retired. Nevertheless, recognition of this variety does not mean that emergent age-based factors that shape social experience should be overlooked. Acknowledging these emergent factors via a conceptualisation of personhood and young onset dementia does not reduce the scope to account for this variety and, in fact, means that we are equipped to account more readily for diversity of experience. The aim cannot be to represent the specific situation of each individual but to devise a model of personhood that more adequately captures the intersections of subjective experience, interpersonal environments and socio-cultural contexts. It has been argued in this paper that it is not possible to grasp these domains without understanding how emergent age-based factors impact upon them. In addition, recognition of the social dimensions of the experience of dementia does not mean that any distinctive biological impacts of young onset dementia should be marginalised; a biopsychosocial approach acknowledges the dialectical interplay between the neurological manifestations of the condition with its psychosocial dimensions (Downs, Clare & Mackenzie, 2006, p. 244).

It must therefore be hoped that research can be undertaken that addresses the requirement to develop a more rounded view of personhood and young onset dementia. This perspective can be of benefit to people with young onset dementia but also offers a more advanced conceptualisation of personhood, accounting for the causal impact of personal characteristics, that is thus more applicable to all people with dementia. An enhanced notion of personhood can then, in turn, provide a more valid sensitising construct with which to address all strands of dementia research.

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Conflicts of interest statement

None declared.

References

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- Alzheimer's Society. (2010). Factsheet 440: Younger people with dementia. Retrieved from http://alzheimers.org.uk/site/scripts/document_pdf.php?documentID=164 (accessed 28 November 2011).
- Alzheimer's Society. (2011). Demography. Retrieved from http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=412 (accessed 28 November 2011).
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders IV*. 4th ed. Arlington, VA: American Psychiatric Association.
- Beattie, A., Daker-White, G., Gilliard, J., & Means, R. (2004). 'How can they tell?' A qualitative study of the views of younger people about their dementia and dementia care services. *Health & Social Care in the Community*, 12(4), 359–368.
- Buron, B. (2008). Levels of personhood: a model for dementia care. *Geriatric nursing*, 29(5), 324–332.
- Caddell, L., & Clare, L. (2010). The impact of dementia on self and identity: A systematic review. *Clinical Psychology Review*, 30(1), 113–126.
- Clare, L. (2003). Managing threats to self: awareness in early stage Alzheimer's disease. *Social Science & Medicine*, 57(6), 1017–1029.
- DH. (2009). *Living well with dementia: a national dementia strategy*. London, UK: DH Publications.
- Downs, M., Clare, L., & Mackenzie, J. (2006). 'Understanding of dementia: explanatory models and their implications for the person with dementia and their therapeutic effort'. In J. Hughes, J. Loux, & S. Sabat (Eds.), *Dementia: Mind, meaning and the person* (pp. 235–258). Oxford, UK: Oxford University Press.
- Edvardsson, D., Featherstonhaugh, D., & Nay, R. (2010). Promoting a continuation of self and normality: Person-centred care as described by people with dementia, their family members and aged care staff. *Journal of clinical nursing*, 19(17–18), 2611–2618.
- Freyne, A., Kidd, N., Coen, R., & Lawlor, B. A. (1999). 'Burden in carers of dementia patients: higher levels in carers of younger sufferers. *International Journal of Geriatric Psychiatry*, 14(9), 784–788.
- Hacking, I. (1999). *The social construction of what?* Cambridge, MA: Harvard University Press.
- Harris, P. B., & Keady, J. (2009). Selfhood in younger onset dementia: transitions and testimonies. *Aging & Mental Health*, 13(3), 437–444.
- Harvey, R. (1998). *Young onset dementia: Epidemiology, clinical symptoms, family burden, support and outcome*. Dementia Research Group; NHS Executive (North Thames). Retrieved from <http://home.kosha.net/~h1415c/report.pdf> (accessed 28 November 2011).
- Kitwood, T. (1990). The dialectics of dementia: With particular reference to Alzheimer's Disease. *Ageing and Society*, 10(2), 177–196.
- O'Connor, D., et al. (2007). Personhood in dementia care: developing a research agenda for broadening the vision. *Dementia*, 6(1), 121–142.
- Roach, P., Keady, J., Bee, P., & Hope, K. (2008). Subjective experiences of younger people with dementia and their families: implications for UK research, policy and practice. *Reviews in Clinical Gerontology*, 18(2), 165–172.

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- Sabat, S. R., Johnson, A., Swarbrick, C., & Keady, J. (2011). The 'demented other' or simply 'a person'? Extending the philosophical discourse of Naue and Kroll through the situated self. *Nursing Philosophy*, 12(4), 282–292.
- Svanberg, E., Spector, A., & Stott, J. (2010). The impact of young onset dementia on the family: a literature review. *International Psychogeriatrics*, 23, 356–371.
- World Health Organization. (1993). The ICD-10 Classification of Mental and Behavioural Disorders diagnostic criteria for research. Retrieved from <http://www.who.int/classifications/icd/en/GRNBOOK.pdf> (accessed 30 November 2011).

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