

# **Shifting dementia discourses from deficit to active citizenship**

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## Abstract

Within Western cultures, portrayals of dementia as ‘a living death’ are being challenged by people living with the diagnosis. Yet dementia remains one of the most feared conditions. The sociological lens of citizenship provides a conceptual framework for reviewing the role of society and culture in repositioning dementia away from deficit to a discourse of agency and interdependence. Awareness of cognitive change, and engaging with the diagnostic process, moves people into a transitional, or ‘liminal’ state of uncertainty. They are no longer able to return to their previous status, but may resist the unwanted status of ‘person with dementia’. Drawing on qualitative studies on social participation by people with dementia, we suggest that whether people are able to move beyond the liminal phase depends on acceptance of the diagnosis, social capital, personal and cultural beliefs, the responses of others and comorbidities. Some people publicly embrace a new identity whereas others withdraw, or are withdrawn, from society to live in the shadow of the fourth age. We suggest narratives of deficit fail to reflect the agency people with dementia can enact to shape their social worlds in ways which enable them to establish post-liminal citizen roles.

**Key words:** dementia, citizen, agency, liminality,

## Introduction

Sociological understandings of the experience of living with dementia are often situated within socio-political discourses. While definitions of citizenship can be located within civil or political domains (Marshall 1950), it is the notion of *social citizenship* that is increasingly relevant to understanding the dementia experience (O’Conner & Nedlund 2016). Citizenship can be considered a social construct, actively shaped over time: ‘*it is a set of social practices which define the nature of social membership*’ (Turner 1993: 4). Understanding citizenship within a wider context than merely civil or political rights provides opportunities to explore what social structures are needed to enable people with dementia to participate in and belong to a community, and the distinctive ways in which

citizenship roles can be enacted following a diagnosis of dementia. This is key in countering discourses which support the covert, or overt, exclusion of individuals with dementia from equal participation in social practices; participating as decision makers and with an equal position in social groups from workplaces to care facilities. Bartlett and O'Conner (2010) propose that social citizenship '*recognizes the person with dementia as an active agent with rights, history, and competencies*' (2010: 39). This gains force by closer attention to Turner's argument that citizenship is a '*dynamic social construction*' the practices of which are shaped by history and political events (Turner 1993: 3). Such dynamic construction can be seen in the global response to the dementia challenge which has shifted discourses of dementia from being centred on individual experiences, to recognising the ways in which socio-political practices and discourses shape the imaginary of dementia.

In dementia studies we see the constructs of social citizenship as helping understand the practice of citizenship in 'ordinary places' (Bartlett 2016: 456). Exploring the macro- and micro-practices of social citizenship enables a more specific understanding of how social rights, obligations and social structures can condition an individual's access as an equal to communities. Applying this understanding to how people with dementia are currently positioned as citizens, often within discourses of deficit, creates means to counter this by, instead, foregrounding the form and types of work people with dementia undertake as individuals and groups so as to re-position themselves as active citizens within their communities.

From a sociological perspective, journeying with dementia will not entail chronological, unidirectional passage along an illness trajectory marked by pathological changes and health-driven structures; rather it is a journey through different life events. This presents risks to, and opportunities for, social interactions. The movement along the illness trajectory is marked by changing social status, some of which can be stigmatising. The sociological concept of liminality provides a lens to explore those social structures which may constrain, or support, opportunities for

people with dementia to move from the liminal state of ambiguity and uncertainty often triggered by diagnosis to a post-liminal state which can enable interdependency and provide the mechanisms for their own agentic actions to support social citizenship.

Medical and social discourses around dementia are bringing the condition of dementia increasingly into public view, together with a growing emphasis on early diagnosis (Prince *et al.* 2011), giving momentum to a socio-political agenda to raise public awareness of the challenges being encountered by people with dementia and their families (Department of Health 2013). Dementia defines a syndrome where symptoms are grounded in decline of brain function; specific symptoms differ across different neurological disease. However, for most people there will be social consequences to a diagnosis of dementia, therefore it is timely to examine the social structures which may shape the journey.

Illustrations in this paper are drawn from a scoping review of literature on social participation in dementia. The review has been used to ground the (*removed for blind peer review*) study which seeks to explore (*removed for blind peer review*) of dementia. For the review we searched health and social science databases for literature reporting the experiences of social participation in people with dementia, living within the community. While we did not restrict country of origin, the literature retrieved mainly reported western experiences. Full details of the review are available from the authors.

## Disrupted trajectories

A universal event in the dementia journey is the disruption triggered by a change in cognitive function. Such disruption may stem from the terror of suddenly not knowing where you are, or the gradual realisation that memory and processing skills are receding. Personal attributions for such cognitive changes are varied and situated within lived experiences (Hurt *et al.* 2011). Nonetheless, changes in cognition mark a key sociological event as the previous certainties of the form and

function of social roles, statuses and planned life trajectories are threatened; the equilibrium of life is disturbed.

Becoming a person with dementia rarely happens at a single time point but rather across time situated within a sequence of physical and social changes either realised by the individual or by others. People may be living with uncertainty about cognitive changes for some time as the fear of being stigmatised can delay seeking help (Bamford *et al.* 2014). Once help-seeking is triggered a series of medical examinations usually precede diagnosis.

Receiving the diagnosis of dementia can be a watershed moment for how the person and others around them perceive their future (Vernooij-Dassen *et al.* 2006, Aminzadeh *et al.* 2007). It moves people along to an uncertain state and a place which is often defined by narratives of deficit. The diagnosis of dementia may be intrinsically linked both by the individual and others as a stigmatised condition (Milne 2010). A dementia diagnosis can be socially discrediting and lead to the person being '*unjustifiably rendered shameful, excluded and discriminated against*' (WHO 2002: 8).

Nonetheless people are themselves seen to use their diagnosis as a disclaimer enabling them to situate dementia and the accompanying cognitive changes as a sickness over which they have no control (MacRae 2010). Such difference in reactions to diagnosis indicates that there may be different personal or wider social structures which enable people to follow different trajectories following diagnosis. For although, a diagnosis of dementia, even if its symptoms have been apparent for some time, places people on a different trajectory to their previously-envisaged selves.

## Liminality

Chronic illnesses, including dementia, are ongoing processes with landmarks, transitions and changing demands. Rolland (1987) described three major phases of chronic illness: crisis, chronic and terminal, each with implications for individual and family adaptation and role changes. The social experiences of living in the 'crisis' period (pre-and post-medical diagnosis), may be considered

as an example of 'liminality' or '*movement between fixed points*' which is '*essentially ambiguous, unsettled, and unsettling*' (Turner 1974: 274). During the liminal state people are often structurally invisible, without status: '*no longer classified and not yet classified*' (Turner 1967: 96). In the post-liminal state they may be positioned within new groups and achieve new status.

For those living with chronic illness and cancer a clearly structured post-liminal state may not be possible. Bruce *et al.* (2014) in their work with people living with cancer, HIV/AIDS and chronic kidney disease identified the concept of '*pervasive liminality*' as the delicate balance of the 'in between' experience. Shields (2015) describes the challenge of focussing on living lives while at the same time having an acute awareness of death and one's own mortality. People living with cancer can experience both acute and sustained liminality (Little *et al.* 1998). Diagnosis leads to the acute liminal state of uncertainty and confusion then over time a sustained liminal state is entered as people adapt and endure their illness; sustained liminality may become a permanent state (Little *et al.* 1998). The concept of liminality in health has also been explored through the experiences of family caregivers. Gibbons *et al.* (2014) report that diagnosis is often a pivotal point which thrusts caregivers into a liminal state, however in dementia the transition is often characterised by a gradual change in roles and social changes.

The concept of liminality within dementia research is relatively under-considered. Sweeting and Gilhooly (1997) in their work exploring 'social death', introduced the notion of a person with dementia being 'a liminal', a non-person who was still making the 'transition from life to death' (1997: 99). Kelly (2008, 2010) working with people with AIDS dementia explored liminality from the perspective of people with a HIV diagnosis and their families. She drew attention to both social and emotional liminal states experienced when people received a diagnosis of dementia, drawing out the sense of uncertainty inherent in liminality. While in her later work Kelly reports people as 'learning to live with liminality' (Kelly 2010: 7), rather than seeing the liminal state as a transitory

state on the route to new roles and status. This has resonance with Bruce's description of pervasive liminality (Bruce *et al.* 2014).

The unsettling and continuing nature of transition in dementia is reported in the findings of Godwin and Poland (2015) where people with dementia living in care homes are described as being in a liminal state. Participants expressed uncertainty about why or how they came to be the home; for some, liminality reduced wellbeing, while others seemed less troubled by the uncertainty. A potential strength of considering liminality as a concept to explore the dementia journey lies in its attention to the social, those social (and therefore shared) rituals and actions which shape experiences. Detailing the social rituals which surround the dementia trajectory can help us see how wider social and political discourses on dementia has an impact on individual experience and the inclusion, or otherwise, of people with dementia as social citizens.

### **Rites of passage**

With the social recognition of illness comes then-recognised rites of passage: movement to status of patient, known or unknown norms of behaviour in medical spaces, changes to roles and responsibilities within families and communities. Van Gennep's (1960) social anthropological concept of staged rites of passage placed the initial focus on social rituals. However, increasingly rites of passage have since been applied to culturally-identified and -managed life transitions. The transition from adolescence to adulthood is marked by social events, both positive and negative which guide child's passage; rites of passage may include a religious coming of age ceremonies or gaining the citizenship right to vote (Scheer *et al.* 2007). Such passages may often be marked by three phases: the pre-liminal phase, the point marking the end of the 'old' status; the liminal phase, where one is 'betwixt and between' statuses; and the post-liminal phase, of re-incorporation or re-assimilation into a new 'normal'.

Rites of passage are vital in moving people through liminality to a post-liminal state. In the dementia trajectory, the pre-diagnosis liminal state is increasingly well-structured. Memory tests, brain scans and being given a diagnosis can all be considered social rituals (see figure 1). If diagnosis is viewed as a rite of passage which enables movement along the dementia trajectory, a ritual hiatus can occur when the diagnosis is either not provided or is denied by the person with cognitive symptoms. Diagnosis is not always straightforward, especially for people with mild symptoms or complex histories, and diagnoses may not be definitive (Phillips *et al.* 2012). An absence of a definitive diagnosis can cause uncertainty and ambiguity (Beard and Neary, 2013; Samsi *et al.* 2014).

A diagnosis socially situates what can be expected of the 'patient' and the behaviour which others will tolerate as part of the disease (Jutel 2009). Disclosing a dementia diagnosis to those outside the family can help people move out of the liminal state and along a journey towards living well with dementia. The decision to disclose a diagnosis may be actively managed by the person as a way of retaining previous status and so potentially protecting the former self. Telling others of their dementia diagnosis creates opportunities to take control of social situations and use strategies to reduce the risk of stigma or embarrassment. Some people take control of social interactions by being explicit about the challenges they face and explaining to others how they can be helped with communication (MacQuarrie 2005, MacRae 2010). Beard and Fox (2008) report that some found being direct about their capabilities was the '*best way to handle things like that*' (2008: 1513). People were also explicit about the types of interaction which were not empowering, as '*when people ask me questions with no context*' suggesting their good insight into the process and work of the social interaction (Beard *et al.* 2009: 230).

Macro structures shape the experience of the dementia journey. For example, the western socio-political emphasis on early diagnosis means that the 'taken for granted' forgetfulness of older age is challenged; memory is repeatedly tested through standardised tests which one passes or fails, with implications for social status. Yet taxonomies of 'acceptable' memory are arbitrary, being historically

and culturally defined (Harding and Palfrey 1997, Katz 2013). A diagnosis of dementia does not change an individual's legal status, yet it is a pre-cursor to significant change. For example, in the UK a person with dementia must declare their diagnosis to the driver licencing authority; their ability to make decisions may be subjected to 'mental capacity' assessments and they are encouraged to put in place legal procedures to identify those who will act on their behalf once their mental capacity is found wanting. There are financial benefits to accepting a label of 'severe mental impairment', for example people with dementia can be "completely disregarded" for the purposes of council tax (a local authority charge payable by residents of properties in England and Wales). In contrast to the UK's 'capacity' approach is that of *self-determination*, as applied in Sweden (see Osterholm 2015)

## Post-liminal destinations

Our scoping review generated evidence for a range of post-liminal states: '*living in the shadow of the fourth age*', '*living as an active citizen with dementia*' and '*living in extended liminality*'. Identifying these distinct trajectories helps construct a sociologically-relevant debate around the dementia journey, bringing into view novel ways to shift discourses of deficit so as to also allow for discourses of active citizenship.

### *Living in the shadow of the fourth age*

#### *The non-citizen*

Ageing and dementia are currently intertwined in most cultures and the social imaginary of dementia is often embedded within the end-stage of the disease where an individual may be seen as frail and dependant, almost wholly unable to participate within their social world: socially dead (McManus and Devine 2011, Zeilig 2013, Cipriani and Borin 2014, Gilleard and Higgs 2014). Here people may be non-citizens, existing without rights, without agency, relying on others for physical care. Such an imaginary resonates with the conceptualisation of the oldest old living in the fourth age in a period of 'decrepitude and dependency' (Kertzer and Laslett 1995).

Western cultures attribute value to the 'productive autonomous self', and how living with dementia is framed may ultimately, if stigmatising, rob the person of their autonomy (Gilmour and Brannelly 2010). Unchallenged or unsupported, this can create tensions and challenges for the attempts of the person with dementia to assimilate changed status and roles framed in this way. Too often, stigmatising attitudes can lead to their exclusion from decisions, care options and social spaces (Batsch and Mittelman 2012). As dementia is more prevalent in older people, these individuals face the double jeopardy of the stigma of ageing and dementia. Dementia is here imagined as stripping the person of their very essence, to become a subaltern a non-person (Gilmour and Brannelly 2010). In the extreme imaginaries of dementia, people are dependent on others to bestow care and compassion on them by virtue of their right to care, through their personhood (Kitwood 1997). Such concepts have resonance with those used by Gilleard and Higgs to characterise the cultural imaginary of the fourth age where people no longer have status, rather they live in a state of being (Gilleard and Higgs 2010). The concept of the fourth age and its imaginary around loss of agency for older people who are '*stripped of social and cultural capital*' (Gilleard & Higgs 2010: 123), may be imposed on the older person by institutions, health care professional and family rather than reflecting any aspects of the internal sense of self held by the older person (Lloyd *et al.* 2014). Others position people with dementia as living as non-citizens, socially dead, within a narrative of complete deficit. By too-readily positioning the oldest old and those with dementia in this place of deficit we risk ignoring the distinction between being and feeling frail (Grenier 2006) and too quickly close the discourse on whether people with advanced dementia can have a citizen status.

When considering the potential for active citizenship within the fourth age the challenge is not only in supporting access to resources for the individual with dementia but also in addressing the stigmatizing attitudes and behaviours of others. While those living with dementia may wish to continue to be agentic citizens the opportunity for this is challenged if others do not recognise this ability or provide opportunities for agency. Kitwood (1997) describes how the actions of carers,

although well-meaning, could lead to a pervasive erosion of the personhood of the person with dementia, their individual and human characteristics, designating this a '*malignant social psychology*' (Kitwood 1997). Knowing people predominately by their diagnosis and not through their personal and socially-situated attributes increases the likelihood that the person with dementia will be given the social persona of 'dysfunctional patient' (Sabat 2002), reinforcing negative discourses.

### *The passive citizen*

Some people living with dementia will be frail and dependent as they live with decreasing cognitive ability and comorbidities; they will need the support of others to manage every day activities, yet being able to make decisions, choosing how and when to exercise rights and responsibilities, demonstrates agency and enacts citizenship status. Social citizenship acknowledges that some people will not be able to be active citizens in the sense of contributing to communities, rather they will be passive citizens. A rights, rather than needs, based discourse enables structural-stigma due to age or dementia diagnosis to be challenged (Bartlett and O'Conner 2010). People can live well in the fourth age as passive citizens if the actions of others recognise and acknowledge the nuanced ways in which people with severe dementia may display agency. People with severe dementia may continue to display embodied agency and with the appropriate social rituals can continue to live as recognised people, passive citizens, with the social rights to good quality care (Godwin and Poland 2015).

For some people, in some life stages moving to live "in the shadow of the fourth age" can be a (destination) which is both realistic in accepting age-inherent physical challenges, while still offering opportunities for agentic actions. Moving into the fourth age may be an acceptable post-liminal state if people are able to review their lives and look back over a positive life (Wolverston *et al.* 2015). To ease the path along the journey to the fourth age there needs to be a realisation and imaginary of the fourth age as being not only a time of frailty, but also a time when some embodied agentic actions remain, even if it requires care workers to support such agency.

## ***Living as an active citizen with dementia***

### *The active citizen*

The narratives of deficit presented above are countered by narratives from people with dementia articulating and defending positive accounts of living well, engaging in loving relationships, preserving identity and self, and living as recognised citizens in their communities (Beard *et al.* 2009, Bartlett 2014).

A growing body of qualitative research suggests that people with dementia continue in social interactions, able to contribute to their communities as a social citizen. Beard *et al.* (2009) report that people with dementia demonstrate ‘*agency by actively accommodating dementia into their lives rather than allowing it to be imposed on them by structural forces*’ (2009: 234), suggesting an awareness, certainly in the mild stages of dementia, of how social structures may facilitate or inhibit agency and citizenship for people.

Dementia support groups provide social structures within which people can perform social citizen roles, through actions that acknowledge both their diagnosis and their right to live free from discrimination in inclusionary ways. Accessing online support groups can help reduce the feelings of fear and social isolation (Clare *et al.* 2008). Interacting whether online or in person can help normalise problems, thereby potentially creating new groups to which the person can move to and belong in (Preston *et al.* 2007). Several studies report that people use humour in their verbal interactions with others (Clarke *et al.* 2010, Langdon *et al.* 2007, MacRae 2010). Humour is often present in liminal life stages and serves various social functions. Humour can control, unite or enable adjustment (Martineau 1972, Ziv 2010) and may be a way of relieving tensions in managing new social identities. In dementia humour may be a way of approaching and dealing with the inevitable losses which accompany changing status and roles: “*Since it is difficult to maintain my old social networks, I have begun to reach out to others online*” (Beard *et al.* 2009: 230).

Social contact with others with dementia provides more than friendship and support for some people as it now it enables them to actively campaign for the citizenship rights of people with dementia. Having the distinct identity of person with dementia can create opportunities to campaign for social change and provide access to service user evaluations. Some have been seen to use their group not only to raise awareness but also to enable them to contribute to debates, *'DASNI (Dementia Advocacy and Support Network International) gives me entrée in a variety of places where I want to participate* (Clare *et al.* 2008: 19). Bartlett's (2014) longitudinal study with people who campaign for social justice through political lobbying and raising awareness of living with dementia presented a balanced view of the advantages but also the challenges of being an active citizen. She concludes *'campaigning can be energising and reaffirming of citizen identity because it (re)located a person within the realm of work'*; however, *'individuals may experience fatigue due to their dementia and oppression linked to normative expectations about what someone with dementia 'should' be like'* (2014: 1300). It should be noted that not all people with mild dementia have the resources or the desire to undertake the work of active campaigning, but equally do not wish to be negatively positioned (Preston *et al.* 2007) objectified (MacQuarrie 2005) nor patronised or over-protected (Beard *et al.* 2009). They do not want the social status of *sufferer* conferred on them (Beard *et al.* 2009).

People with dementia may participate as socially active citizens, giving to others, in ways not directly linked to their dementia and at a micro-level. Beard *et al.* (2009) recount the case of a man who had always been a basketball coach and who continued this activity after his diagnosis. Phinney *et al.* (2007) present a similar example of a man who had worked as a musician who continued to make music and to share this at his dementia group. However such active citizenship may need to be supported by others. Opportunities to remain a productive part of family life were sometimes created by the actions of family members: *"I leave her grandchildren with her because one it alleviates the fact she feels useless. You know, she's now, she's great with the kids"* (Clarke *et al.*

2010: 109), yet the person with dementia must also be agentic in taking up the opportunity for active citizenship.

Many people with dementia give positive accounts of living with the condition emphasising the continued abilities and contentment with life while downplaying cognitive difficulties. Steeman *et al.* (2007) in critically exploring the positive narratives of older people living with mild dementia, suggest that there may be a constant balancing of 'being valued' against 'being worthless'. While people with dementia strive to affirm their competencies other may devalue their abilities and roles (Steeman *et al.* 2007: 126). Being confronted by losses and lacking the support of others to be active citizens can lead to restricted opportunities for citizenship, even while the person is striving to live as an active citizen with dementia.

#### *Restricted citizen*

The cognitive abilities of a person with dementia decline over time. Family members are expected to take increasing responsibility for making proxy decisions for their relative (Samsi & Manthorpe 2013). However some people with dementia report that this happens too-readily, leading them to feel 'put down' (Langdon *et al.* 2007: 995). In these situations opportunities to be an active citizen are restricted rather than supported by others. Not being listened to or consulted about decisions appeared to lead to frustration and anger, "Oh I was furious...not to have talked to me...we think this is best for you" (MacQuarrie 2005: 433). Being central to decision making, however minor that decision may be, and being offered subtle support to enable purposeful contribution to the decisions, were all acknowledged as important, especially as people recognised their changing cognitive abilities (Fetherstonhaugh *et al.* 2013).

People with dementia may be striving to be active in their families and communities but the actions of others constantly constrain their opportunities for agency. This can generate feelings of being disempowered when others take over tasks, and restrict opportunities for access to meaningful or

enjoyable activities due to others perceiving them too risky (MacQuarrie 2005; Clarke *et al.* 2010). Having others restrict opportunities for people with dementia to be agentic, reflects the many frustrations and constraints experienced by those living in the shadow of the fourth age. Such uncertainties and threats to self, alongside the desire to remain an active citizen, are succinctly captured in the Beard and Fox (2008) study exploring how people with Alzheimer's disease resist becoming socially disenfranchised. They report one participant as saying '*I still have enough intelligence, you know, to be a person and not just someone you pat on the head as you go by... it's devastating and it takes away your sense of self*' (Beard and Fox 2008: 1516).

Attempts to participate as citizens by the person with dementia may be refuted by family (Preston *et al.* 2007, Clarke *et al.* 2010, Clemerson *et al.* 2014), illustrating the need for effective, understanding support systems if people are to enact citizenship roles. Families are often left to 'muddle through' and may struggle to find a good balance between protection and enabling of their relative with dementia. Retaining trusting relationships and sustain effective social networks is important at a time when many people can experience depression and withdrawal from previous social networks (Burgener *et al.* 2015).

### *Living in extended liminality*

#### *Uncertain citizen*

Literature exploring liminality in chronic illness frequently refers to the concept of on-going liminality: pervasive liminality (Bruce *et al.* 2014); sustained liminality (Little *et al.* 1998). These liminal states are presented as non-problematic, without need to be resolved. We suggest that being in an extended state of liminality for people with dementia may be problematic as it may constrain opportunities for fulfilling the roles and accepting the rights of being an active citizen with dementia. If a diagnosis is not accepted or the social structures, such as family and health care services do not assist the movement to either being a passive or active citizen people may potentially become

'stuck' in extended liminality; a place where roles are contested and rights may not be readily accessible because the person one does not have the status of 'person with dementia'. This post-liminal state is characterised by continuing ambiguity and uncertainty particularly about the diagnosis. Either the 'truth' of the medical label of dementia will be contested, or opportunities are not taken to disclose the diagnosis (Aminzadeh *et al.* 2007); an act seemingly necessary for enabling an active citizen's participative work. Nonetheless the cognitive decline inherent in dementia means that changes in roles and status can eventually become inevitable.

Some people have a confirmed diagnosis but are unable to acknowledge or act on this, perhaps relating to the agency they had in obtaining the diagnosis. Living within a state of 'extended liminality' can have negative social consequences, as failing to receive or act on a diagnosis of dementia may mean masking the symptoms of cognitive decline. While people are able to mask their difficulties in social interactions and social roles they can continue to pass as an intact self. However, if their ability to mask difficulties declines and others notice their potentially-deviant behaviours, the risk of being stigmatised increases. To avoid such risks to self, people may '*isolate themselves from others*' (Robinson *et al.* 2005: 341), thus reducing opportunities for exercising their social citizenship.

More fully exploring the 'extended liminality' state may help delineate the social structures which block successful transition to a post-liminal place, and so enable us to develop new ways to support those with dementia and their families in ensuring agentic movement along the dementia journey.

### **Critiques of the citizen roles**

In this paper we have drawn predominantly on literature which contextualises the western experience of living with dementia. We do, however, acknowledge ethnic variations of experiences within western (Dilworth-Anderson and Gibson 2002, La Fontaine *et al.* 2007) and non-western illness experiences (Cipriani and Borin 2014).

We accept that our representation of the dementia journey is linear whereas there can be sudden or gradual changes in cognitive function, alongside changes in physical abilities due to co-morbidities and that individual experiences will certainly be shaped by micro-social events. Changes in emotional well-being with depression may occur in those living with dementia making it difficult to enact agentic decisions. Further changes in social networks may be due to death of older friends and re-location connected to frailty. Nonetheless theorising liminality here provides ways to understand the impact of these physical, emotional, social and cognitive changes. Conceptualising post-liminal states provides new ways to understand the experience of moving along the dementia journey and to acknowledge positive as well as negative narratives in dementia.

## Conclusion

The concept of liminality, being in a place of uncertainty and ambiguity, provides novel ways to understand the structures which move people along the dementia journey to post-liminal states. Bringing to the fore the post-liminal state of living well with dementia makes it possible to illustrate the various citizen roles held by people with dementia (passive or active citizen) as well as factors which may inhibitor opportunities to fulfil such roles (restricted or uncertain citizen).

By accepting and disclosing a diagnosis people are creating opportunities to use the diagnosis as a tool for explaining any adaptations they may need in order to remain active in their social networks. Recognising and providing opportunities for the development of remaining personal attributes and skills, enables positive narratives rather than focussing on the deficits inherent in dementia. Working within a framework of social citizenship enables a more specific understanding of how social rights, obligations and social structures can condition an individual's access as an equal, to communities. Applying this understanding to how people with dementia are currently positioned as citizens, often within discourses of deficit, creates means to counter this by, instead, foregrounding the form and types of work people with dementia are undertaking as individuals and groups so as to re-position themselves as active citizens within their communities.

The social standing of the person with dementia may be more fully recognised by creating ways for giving citizenship more prominence in the social imaginary enabling their potential for continuing citizenship to be realised conceptually and in everyday practices, despite their changing expectations of cognitive capacity. By further exploring the ways in people may sustain such agentic roles in the face of change it may become possible to identify successful ways of managing the status transitions linked to receiving a diagnosis of dementia, enabling movement through the liminal phase. This opens up the possibility of moving interventions beyond behaviour modification to those which empower people with dementia to be active citizens who, therefore, can retain participatory roles in their social worlds.

### **Acknowledgments**

We thank our reviewers whose insightful comments on an earlier version enabled us to develop our conceptual ideas thereby improving this paper.

### **Funding**

This work was supported by the Economic and Social Research Council/ National Institute of Health [grant number ES/L001802/1]. This article presents independent research funded by the National Institute for Health Research (NIHR). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

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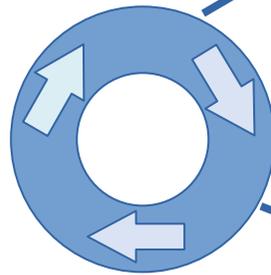
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**Figure 1: Liminal States in Dementia**

**Rituals of becoming a person with dementia**

- Discussions acknowledging possible memory lapses
- Standardised memory tests
- Brain scans
- Formal confirmation of diagnosis or non-diagnosis
- Status as mental health patient

**Liminal state (uncertainty and ambiguity)**



**Post-liminal state**

**Characteristics of post-liminal state**

Living in the shadow of the fourth age	Acknowledging frailty Agentic interdependence Preparing for the future
Living as an active citizen with dementia	Disclosure of diagnosis Continuing social status Developing new networks Being a social citizen
Living in extended liminality	Ambiguity of diagnosis Not able to develop new networks Becoming isolated

Post-liminal state influenced by:

Cultural beliefs, Reaction/expectation of others, Acceptance of diagnosis

Co-morbidities, Social capital reserves.