



Preserving personhood: The strategies of men negotiating the experience of dementia



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ABSTRACT

An understanding of dementia requires sensitivity to the complex breadth of factors that comprise the person's experiential and social context. This is necessary to ensure that academic and public perspectives on dementia are not subsumed under homogenising discourses that prioritise the neurodegenerative basis of the condition. Gender is one such factor of this 'social location' that must be acknowledged. Cultural standards of masculinity have particular impacts upon men with the condition, thus generating distinctive challenges. This article draws upon qualitative research that included joint interviews with 14 men with dementia and their carers. The analytical focus is on the perspectives of the men with dementia and the strategies with which they respond to the condition. These perspectives are organised via four themes: *remaining unmoved*, *fighting back*, *emphasising social contributions*, and *redefining services*. This enables exploration of how men adopt particular strategies to preserve their own personhood, which include equitable resilience, but also more agential measures to counter the influence of the condition. It is concluded that an approach to dementia research that is more sensitive to masculine-gendered experience is required so that the experience of men with the condition can be conveyed more cogently.

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Introduction

Dementia is a neurodegenerative condition that impacts, inter alia, upon the person's memory, communication and behaviour (Hughes, 2014). It is estimated that 850,000 people in the UK have dementia and this figure is predicted to increase (Alzheimer's Society, 2014). Dementia therefore presents substantial challenges in terms of its experiential impacts upon people living with the condition. It also raises significant concerns in relation to policy and practice endeavours to cope with the increasing prevalence of dementia. Enhanced understanding of the condition is required so that people with dementia and their families can receive optimal modes of support. This article sets out to contribute to this enhanced understanding by exploring the strategies that men with dementia employ to preserve a positive sense of self-worth and identity in response to the impacts of the condition. The influence of gender upon the experience of men is an under-examined feature of social scientific health research: "Gender, the complex of social relations and practices attached to biological sex, is one of the most important socio-cultural factors influencing health and health-related behaviour, but rarely is men's health deconstructed through the

lens of gender" (Evans et al., 2011:7). The tendency to overlook the influence of gender upon experience is strongly reflected within dementia research (Bartlett et al., 2016).

There is a clear propensity, for example, within qualitative research focused on the experience of dementia to recruit a mixed-sex sample of participants. Themes relating to identity, experience or relationships are then presented, but in the pursuit of thematic unity the extent to which these phenomena might have been shaped by gender remains unexplored. Accordingly, experience and relationships are addressed in gender-neutral terms. Although the empirical focus on gender has been limited within dementia research, there has been recognition that the 'social location' of people with the condition warrants close consideration. Social location highlights that sensitivity to the complexity of people's situations requires recognition of how characteristics such as gender, ethnicity and socioeconomic status influence identity and experience (Hulko, 2009; Bartlett & O'Connor, 2010). While it is a challenge to ascribe distinctive gender-related factors to experience, the alternative approach (overlooking the influence of this key feature of social location) can only offer a distorted and inchoate grasp of the experiential domain.

Underneath the absence of a gender-specific account of dementia, the requirement to understand the experience of men with dementia raises distinctive matters for consideration. The contemporary Western cultural context places particular value upon personal qualities such as

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rationalism, cognitive competence and economic productivity (Post, 2000). In contrast, people who do not measure up to these standards i.e. those who do not work, or who are dependent upon care, are labelled as defective (Weicht, 2015). These standards mean that older people and those encountering health problems are at risk of feeling undermined by these cultural standards. While these challenges will affect both men and women, it can be argued that the aforementioned standards present particularly acute difficulties to men, as masculinity is identified with values of resilience, independence and instrumental competence. This is associated with the patriarchal basis of societies, which reinforces constructions of masculinity aligned with dominance. Values of physical and mental strength, courage and fortitude are thus “integral to the calculus of power by which a patriarchal system operates” (Buchbinder, 2010:35). An illness that generates a sense of vulnerability and passivity thus presents a substantial challenge to the concept of the valuable and ‘proper’ man. A neurodegenerative condition such as dementia, which impacts upon cognitive performance, accordingly presents particular challenges by threatening masculine ideals of competence, autonomy and control (Coston & Kimmel, 2013).

A very limited number of research studies address the influence of masculinity upon the experience of dementia directly. With reference to a formal care setting, Bartlett (2007) presents a case study of a man who is a resident in a nursing home. A traditional masculine identity was demonstrated in his accounts of how he related to other men in the home. A certain degree of manliness was also noted in his use of humour when discussing being bathed by a woman. Phinney et al. (2013) present experiential themes from a qualitative study that included two men with dementia and their families. These themes were identified to be closely associated with traditional masculine roles. Work-related pursuits were a prominent theme in discussions with the men, with this often focused on activities that had filled their lives in the past. However, activity also presented a sense of ongoing engagement with life and offered a sense of continuity. This helped the men to feel a sense of remaining connected to the world.

Sensitivity to the complexity of experience must acknowledge the breadth of relational and social factors that comprise an individual's circumstances. It is important to note that particular characteristics are not unitary phenomena; for example, a range of factors such as age, economic status and social context influence constructions of masculinity (Courtenay, 2000). It should also be recognised that the experience of older people tends to be addressed in homogenous terms, with assumptions of decline limiting the apprehension of their wider dispositional qualities (Higgs & Rees-Jones, 2009). If the complex range of factors that shape experience is underplayed, then dementia research is at risk of contributing to homogenising discourses that elevate neurodegeneration to the principal experiential basis of the condition. The requirement to endorse the relational and social basis of experience relates to the concept of personhood, which is defined as “a standing

or status that is bestowed upon one human being, by others, in the context of relationships and social being. It implies recognition, respect and trust” (Kitwood, 1997:8). While highly influential, Kitwood's model of personhood has been critiqued for understating the active role the person plays in shaping their experiential circumstances. The focus on a status bestowed by others confers a passive status upon the person with dementia; however, it is important to recognise the active role the person takes in defining and preserving their own personhood (Baldwin & Capstick, 2007; Higgs & Gilleard, 2015).

This article sets out to offer some counterbalance to the lack of a masculine-gendered portrayal of the experience of dementia, while also accounting for the active role that men play in shaping their experiential circumstances. Data from a qualitative study that included 14 men with dementia are utilised, and the analytical process (discussed below) led to the identification of key personal strategies. The interrogation of these interrelated themes enables exploration of how men with dementia seek to preserve their own personhood in response to the impacts of the condition.

Materials and method

Sample

This article draws from data collected as part of a UK-based qualitative research study that included 14 men with dementia and their spousal carers. 13 of the participating dyads are mixed-sex and married, while one is same-sex and not married. One participant is Afro-Caribbean, while the others are White-British. The men covered a broad age-range, with the youngest participant 58 years of age, the oldest 89 years. Based on educational background and occupation, an assessment was made of the men's social class. Two participants had attended university; the other respondents had completed secondary education. The principal researcher also noted the level of understanding demonstrated by each participant, and their capacity to engage with the interview process: this informs the judgement of the degree of the condition displayed in the table. (See Table 1.)

Respondents were recruited via National Health Service (NHS) Trusts in England, and dementia support groups. The men were selected as they had been diagnosed with dementia, still lived within their family home and had the mental capacity to take part in a qualitative interview with their partner. Relationship status could of course intersect with masculine-gendered experience: the orientation of this research means that the experiences of those who were single, divorced or widowed were not explored. Ethical clearance for this research was granted by the NHS Research Ethics Committee. Written consent was obtained from all participants during arranged discussions, prior to convening the interview.

Table 1
Participant characteristics (at date of first interview).

Name	Age	Condition	Length of time since diagnosis	Degree of condition	Social class	Principal occupation ^a
Oliver	58	Alzheimer's	6 months	Mild	Working	Skilled manual
Paul	60	Alzheimer's	6 years	Moderate	Working	Driver
David	64	Alzheimer's	6 months	Mild	Middle	Business owner (distribution)
Timothy	64	Lewy body	6 months	Mild	Middle	Fashion
Nicholas	66	Alzheimer's	1 year	Moderate	Middle	Teacher
Michael	67	Alzheimer's	1 year	Moderate	Working	Driver
James	67	Alzheimer's	2 years	Mild	Working	Skilled manual
Simon	75	Alzheimer's	1 year	Moderate	Working	Manual
Philip	75	Alzheimer's	5 years	Moderate	Working	Skilled manual
Robert	76	Alzheimer's	1 month	Moderate	Working	Skilled manual
Patrick	78	Alzheimer's	1 year	Moderate	Middle	Sales
John	82	Vascular	3 years	Moderate	Working	Manual
Sam	83	Alzheimer's	3 years	Mild	Working	Pub landlord
Marcus	89	Alzheimer's	5 years	Moderate	Middle	Armed forces

^a Only David was still in employment over the course of the research.

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