

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

## 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 equable 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.

**Key words:** dementia; gender; masculinity; personhood; social location

## 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 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 (Author, 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 man to feel a sense of remaining connected to the world.

Sensitivity to this complexity acknowledges the breadth of relational and social factors that comprise an individual’s circumstances. It is also 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 also 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.

### Table 1: Participant characteristics (at date of first interview)

Name	Age	Condition	Length of time since diagnosis	Degree of condition	Social class	Principal occupation <sup>1</sup>
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

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.

### Data collection

Men with dementia and their carers were interviewed together: semi-structured joint interviews took place in participants' family homes and had a mean duration of 70 minutes. The research set out to obtain an understanding of the experience of men with dementia, via extensive respondent accounts on spousal relationships, relationships with other family members, and the professional support they were accessing. An interview schedule addressed the impact of the condition on the spousal

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<sup>1</sup> Only David was still in employment over the course of the research.

relationship, family relationships more widely, and also how the couple were negotiating professional support. This provided a broad framework for the discussions: while the interviewer offered questions and prompts in line with this framework, respondents were free to raise matters that were important to them. Each set of interviewees was interviewed twice to ensure that extensive experiential insights were obtained, with there being a six-month interval between these interviews<sup>2</sup>. Interviews were audio recorded and transcribed verbatim.

It also has to be recognised how the joint interview setting shapes the expression of respondents' perspectives. The social pressures imposed by the co-presence of interviewees will influence the expression of personal viewpoints (Taylor & De Vocht, 2011). The gendered basis of the dyad will also exert an influence (Seale et al, 2008). While the individual viewpoints of the men with dementia are the focus of this article, these views will inevitably have been influenced by the interview context, which included the spousal partner (and a male interviewer).

### Data analysis

The joint interview process generates several layers of data, enabling access to the views of men with dementia, their spousal carers, and also interactions between the two participants. In keeping with the endeavour to obtain extensive accounts from respondents, narrative analysis (Riessman, 2008) was undertaken of transcripts. The aim of the analytical process was to establish the key subjective themes expressed by the man with dementia and the carer respectively, but also how these narrative themes intersect within conversation. This process not only enabled exploration of how respondents constructed stories related to their personal experience, but also how a shared perspective of the relationship is negotiated via talk-in-interaction (Squire, 2008).

This article focuses specifically on the representation of the accounts expressed by the men with dementia within these joint interviews.<sup>3</sup> A process of close reading of

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<sup>2</sup> For health-related reasons, James, John and Sam did not participate in a second interview.

<sup>3</sup> The focus on how identity is maintained (and challenged) within interactional exchanges has been explored elsewhere (Author, 2017).

interview transcripts and manual noting was performed by the principal researcher. Commonalities of narrative theme were identified across the interviews, and interpretative judgements were also made with regard to the experiential salience of these topics. This enabled the identification of key elements in each interview, and these were then organized with reference to similarities across the interviews (while also recognizing complexities and divergences within these identified themes).

The process of analysis must also be attuned to both the immediate and wider contextual basis of narrative: it is vital to acknowledge how narratives are directed to co-present individuals, and are also shaped by social and cultural factors. This relates to a key concern within this article; that is, to what extent does an individual's narrative represent their 'real' subjective preferences? Additionally, to what extent is this narrative influenced by relational and social pressures associated with masculinity and personal identity? These are of course complex and potentially insoluble matters, but an experiential account can only be complete if these pressures are taken into consideration. There is no pre-social basis to a person's expressed perspective: an account is never a unitary phenomenon but is 'polyphonic', with the influence of social discourses an inextricable feature of expressed subjective perspectives (Sullivan, 2012).

## **Results**

Different strategies to address the impact of the condition were apparent in the accounts of the men with dementia. These strategies relate to the aim to preserve personhood within the man's immediate lifeworld: the domain of interpersonal relationships and interaction. They also relate, however, to the impact of wider social discourses and cultural standards upon the endeavours of men with dementia to maintain their preferred identities (Charmaz, 1994). In addition, it should be recognised that these are not discrete, hermetic strategies. The interrelationship between these strategies is accordingly highlighted as the article progresses.

### Remaining unmoved

Among the repertoire of responses to the influence of dementia was an expressed acceptance of circumstances. This can be argued to reflect a stoical personal strategy,

which relates to quiet endurance and an attitude of acceptance of particular factors beyond the person's control (Moore et al, 2013). This highlights the requirement for men to remain strong in conditions of adversity. Accepting the condition with a stoical outlook does not therefore relate to passivity; instead it demonstrates the ability to cope effectively, thus enduring difficulties independently. It also enables the men to reinforce their own sense of personhood by showing that they are unmoved to any substantial degree by the condition. They therefore *remain the same person* despite the influence of dementia.

This approach is captured by Robert's statement below, which expresses a dispositional quality of an unemotional and positive acceptance of his situation. Robert's reference to the fact that all people *have their circumstances* shows how he feels that encountering challenges is not exclusive to him:

We all have our circumstances and that sort of thing, you get on with it. You see, I'm not a moaner.

(Robert)

A similar strategy is presented in a short statement by Marcus, who refers to the condition with reference to the ageing process. The fact that the ageing process is outside anyone's control means that worrying would be fruitless:

You can't stop the ageing process, no point worrying about it.

(Marcus)

Marcus is the oldest member of the sample at 89 years of age and it is possible his perspective relates to this age-related factor. When a person has substantially exceeded the standard period of life expectancy then this is potentially conducive to a stoical acceptance of declining health. Such an approach however was not exclusive to older members of the sample. Timothy, at the age of 64, also states that he accepts the condition and offers the phlegmatic view that it's likely that a person will experience a problem with their health at some point in their life:



I just think it's one of those things. You're going to have something, trouble with your heart or trouble with something. So you know it's - okay it's a problem but it's not the end of the world and I don't think about it. It's there, it's there.

*(Timothy)*

Sam extends this view further and asserts that his situation is actually preferable to that of some others: he employs a 'downward comparison' when he refers to those who are unable to engage in the level of activity that he undertakes. Focusing on the positive enables him to offer a resilient identity, by focusing on what he is still able to do, rather than anything that has been lost (see also Beard & Fox, 2008). The maintenance of a regular walking routine indicates that Sam is maintaining self-discipline and some control over his circumstances, in line with masculine imperatives (see also Davidson, 2013). While Sam draws upon an example of activity, his focus is on how the condition has not affected his scope to engage in a regular task:

But health-wise I'm all right. I walk up twice a day to the paper shop. It's only at the top of the road. And then I think there's other people that can't walk isn't there. So you've got to be grateful for that.

*(Sam)*

The person with dementia's background and personal circumstances also interrelate with their response to the condition. For example, Oliver suggests that his attitude towards the condition is shaped by experiencing previous health conditions. Having survived an aggressive cancer means that he regards the onset of dementia as "just another setback":

I had a very aggressive bladder cancer, grade five and I took that on the chin and every year we were on the boat it was a bonus to me, where a colleague of mine where I used to work, he had a grade two and he only lasted six months, so to me I've got more years than I should have if you get what I mean, so this is just another setback.

*(Oliver)*

It is not just the biological impacts of the condition that prompted a narrative strategy of equable resilience. Paul discussed how he encountered social responses, which

were predicated on a lack of understanding, but also expressed a humorous acceptance of these responses:

People, some people they don't know what dementia is.  
"Dementia, what's that?" They look at you daft, so I just laugh.  
(Paul)

The perspective of resilient acceptance offered by these men with dementia is consistent with the perspective presented by men in other health-related studies. For example, Gibbs (2005) found that 'hegemonic masculinity' (defined by appearing strong and not showing pain) shaped the experience and perspectives of men with arthritis. With reference to this principle, it has also been argued that dismissing concerns related to health matters enables men to sustain their status within a society that positions them as stronger than women (Courtenay, 2000).

### Fighting back

More active measures in response to the impacts of the condition were also presented by the men with dementia via which they set out to manage or resist the condition. This shows that a stoical acceptance of the influence of dementia was not always sufficient. On occasions, it was necessary to offer a more agential response to the condition: a degree of 'fighting back' was necessary to sustain a narrative of *being the same person*. The tendency to make appeals to active endeavours to sustain a positive identity is in accordance with the findings of Charmaz (1994) who addressed the relationship between chronic illness and masculinity, highlighting how men cope when faced with health-related challenges. Strategies adopted by men related to traditional views of male identity, including the adoption of an active, problem-solving stance, as well as the emphasis on personal power and autonomy.

James discusses the way in which he actively endeavours to maintain his cognitive performance: to support his well-being, he states that he undertakes competitions in magazines, although he does note that his performance is declining. Acknowledging the negative impacts of the condition in this instance relates to an active approach to countering the influence of dementia:

I do as many competitions as I can. For the brainwork – like in ‘Take a Break’, all the competitions in there. Six/eight months ago, two days I’d go through it. It’s taking me seven days now. It’s getting worse and worse you know, because of the concentration levels. I can’t seem to hold my concentration, it’s getting very short. I’m still trying to stimulate and keep my brain going.

(James)

David also sets out to counter the impacts of the condition, but in his case it is through close adherence to his medication regime:

I felt it’s up to me to try and do what I can do. And listen to what they have to tell me. To ensure that I take the drugs at exactly the right times that they told me to have them. I go to work in the mornings and the first thing I do is take my drugs, so I know I’ve done that. And then I’m pleased with that, because the drugs, the Aricept has just really sort of turned me around. It has had a great deal of effect on me, it’s improved me completely.

(David)

While he is following the recommendations set out by a health professional there is still a clear sense that David is investing this process with his own agency. This shows how he is seeking to take control of his situation and actively address the influence of the dementia and its associated uncertainties. To some extent David converts his condition into a technical issue that can be resolved through commitment and self-discipline (see also Gibbs, 2005). This approach also enables him to make an appeal to *complete improvement*, thereby helping him to assert a return to his pre-diagnostic sense of self (Charmaz, 1994). He therefore adopts a position of active resistance to the condition, while also avoiding any negative labels associated with dementia. It should also be noted that other circumstantial factors might intersect with strategies to resist the influence of the condition. David had been recently diagnosed with dementia: his appeals to the positive effects of the drugs, and his focused input into the process of their administration, could thus relate to this recent disruption to his circumstances.

Active endeavours to resist the impact of dementia do not just relate to attempts to address the cognitive manifestations of the condition. For example, Timothy discusses his gym membership below and his views demonstrate a desire not to be excessively

defined with reference to dementia. This shows how activity also pertains to attempts to address the social perceptions of other people, which he contemplates with self-deprecating humour. The reference to being perceived as ‘a nutter’ also demonstrates the distinctive threat presented by dementia i.e. the anticipated deleterious impacts upon cognitive performance:

You have to be careful, because I was telling everyone that I had dementia, then they automatically thought that he’s got dementia. And so then I decided to go to the gym, because when people know I go to the gym, they’ve got more idea as to what the situation is. I could go out and say “Oh well I’ve joined the gym now”. It was a means of conversation, and not just saying, “By the way do you know that I’m a nutter?”

(*Timothy*)

The onset of dementia can generate concerns with regard to a loss of status and roles (Langdon et al, 2007). Timothy’s gym membership appears to be an active step to develop a social attribute, so that others do not define him excessively by his dementia. This shows that even a relatively simple active measure can help to bolster a person’s identity and esteem, sending out an indication to other people that the person with dementia has interests and skills beyond their condition. As noted under the previous heading, Sam draws upon an example of activity (walking to the shop) to show that he is still the same person who is still able to engage in regular tasks (he remains unmoved). Timothy’s strategy is similar, but he is taking on a new activity and expressly states the aim to counter the perspectives of other people (he fights back).

It is also notable that, as highlighted under the previous theme, Timothy expressed a stoical acceptance of the condition’s impact, stating a phlegmatic view that poor health was an intrinsic feature of life. Timothy’s perspectives show how the complexity of personal circumstances render these different strategies (*remaining unmoved* and *fighting back*) compatible. He stoically accepts the dementia diagnosis and biological effects of the condition on his personal health, and accepts that this is based upon the contingencies of the natural world. Nevertheless, the social labels associated with the onset of his condition are of concern. Timothy therefore endeavours to resist the potential judgements of others via the adaption of his lifestyle and the presentation of an active identity. This valuably highlights that personal strategies for preserving

personhood are not discrete and mutually exclusive categories. It is possible to draw upon various strategies as appropriate in the pursuit of an enduring and consistent sense of identity.

While the requirement to present an agential social persona could relate to masculine imperatives, it's also crucial to recognise how other characteristics will shape the experience of the condition. Timothy is 64 years of age and is therefore categorised as having young onset dementia (people with dementia up to age 65). As Timothy is relatively young to have been diagnosed with dementia, this will also relate to cultural norms on expected levels of performance and functioning for a person of 'working age'. Cultural constructions of old age tend to provide a marker between *the old*, whose achievements reside in the past, and *the young*, who are continuing to shape their circumstances and future through ongoing activity (Author, 2015). Increased longevity and changing societal expectations on ageing have led to the suggestion that a burgeoning 'third age' now shapes the experience of older adults (Gilleard & Higgs, 2005). These societal norms will therefore intersect with the experience of dementia. When culturally-shaped personal expectations associated with the third age, i.e. enduring good health and high levels of activity are anticipated, then this could compound the challenges for younger men with the condition. Undertaking a physical pursuit might therefore be particularly crucial for Timothy, as this helps him to avoid feeling that he is being prematurely aligned with the 'fourth age' (the period of illness and decline associated with 'extreme' old age) (Weiss & Bass 2002).

### Emphasising social contributions

The discussion of Timothy's gym membership above shows how social perceptions shape the approaches adopted by men to sustain a positive sense of personhood. A further key topic that was identified from the interviews was the requirement for men to assert the contributions that they made to assist other people. This builds upon the previous themes and underscores the social basis of strategies to address the influence of the dementia. Discrete self-focused strategies are not necessarily sufficient to underpin the maintenance of a positive self-identity. What is also crucial is to relate how one's active endeavours make a positive impact on other people. Emphasising positive social contributions allows men with dementia to subvert the

expectation that they will be the recipients of assistance, thereby resisting the sense that they are passive and dependent. The contributions discussed by men within the interviews related to: the spousal relationship; helping others in specific settings such as support groups; and also more extensive and abstract contributions made to society via employment.

Helping others was stated by respondents as a key personal requirement (see also Menne et al, 2002); for example, Oliver asserts his need to assist within the spousal relationship, maintaining a reciprocal mode of support between him and his partner. This therefore positions him as someone who is not exclusively in receipt of support:

She's looking after me and she's always going to look after me,  
so I have to help her as well don't I.

*(Oliver)*

Helping others also represents an expression of agency that links action to meeting broader social requirements. For example, Simon feels that his principal role at a walking group is to help others whose needs are greater than his own. To be there for others enables alignment with the selfless virtue of giving (Author, 2011), which accordingly positions the person in direct contrast to someone who needs care:

I said "if I am here to help you people, it's no good me just lying  
back and saying nothing and going home". I've got to help them.  
They are people who have got more trouble than what I've got.

*(Simon)*

While the perspectives above show how contribution relates to concrete interpersonal relationships, discussions on paid employment provided a means by which men could demonstrate an extrinsic contribution to wider society (Gradman, 1994). In this study men with dementia often made reference to working roles that were undertaken in the past. Philip, Simon and Marcus, for example, recalled times that they had spent in the armed forces. This had an adventuresome quality with Philip and Simon recalling being posted abroad, and Marcus discussing his experience flying in bomber aircraft. Similarly, Michael made several references to his former role as a commercial driver and the extensive degree of travel this involved:

I used to run about all over, thousands of miles, up to Russia.  
*(Michael)*

Recalling former endeavours can enable men to assert their former contributions, even when the dementia has limited their current levels of activity. This is in accordance with the findings of Phinney et al (2013), who found that the men with dementia in their study had enacted traditional masculine identities in their working life, underpinned by a sense of accomplishment and hard work.

Below Philip combines discussions of activity and contribution: acknowledgement of a decline in his current activity level leads to an assertion of his former levels of endeavour. He discusses how going for a walk now presents a challenge, and he accordingly does not venture far. (Further to the presented quote below, he also stated that he fears getting lost). Philip nevertheless states that he can recall the experience of hard work. In this way he demonstrates that his current situation does not represent the totality of his life, and that he formerly applied himself within his working roles. This can, again, be interpreted as an assertion that he has met the moral standard of economic contribution to wider society over his lifespan. The stage of the condition could therefore shape the nature of appeals to social contribution. When the dementia is at a stage that means men are less socially active than previously, this could generate pressures to underscore former contributions:

The biggest one is I wander down there, just have a look and go up the bank a little bit and think 'Oh, this is too much like hard work' and go back home. But I can remember what hard work was.

*(Philip)*

David was still actively engaged in employment over the course of the interviews. This provides him with the opportunity to assert his ongoing economic inputs, which accordingly means that he does not have to rely on appeals to former contributions. The following quote demonstrates work offering David the scope to feel a sense of contribution via a busy and involving day. It is not just the case, however, that involvements within the sphere of employment relate to hard work. Effective contributions also require skill and competence: "being good at what you do" (Coston

& Kimmel, 2013: 197) is a strong masculine-gendered trait. Being perceived as competent is not, of course, only important to men; but cultural pressures upon women tend to focus on their ability to sustain positive relationships, rather than instrumental abilities (O'Connor, 1995). David's reference to hitting a nail with accuracy shows how his role at work is underpinned by enduring manual competence:

I've had a busy day today. We ship an awful lot of barbecues all over the country...you have to wrap them, put timbers under these big concrete barbecues and nail them together so they don't fall off on the lorry and things like that. I often get that job. I can hit the hammer on a nail dead-on every time.

*(David)*

It is also important to note that cultural constructions of masculinity are not fixed and static: for example, cohort effects are likely to have a key influence (Gilleard & Higgs, 2005). Although labour market conditions have changed significantly over recent decades, all of the men in this sample would have commenced their working lives in a context where the man as principal (or even lone) breadwinner within the family was the norm. The ongoing erosion of this expectation shapes perceptions of gender-related roles and identities and will accordingly affect the experience of dementia in the future.

### Redefining services

The approaches that men adopt towards their association with professional support are influenced by the aforementioned narrative strategies: the endeavour to sustain a self-sufficient and agential persona shapes perspectives on their engagement with services. The men with dementia generally expressed a favourable view of professional support they were receiving, whether this was via a psychiatrist, community psychiatric nurse, day centre, befriending/domestic service or support group. It must be acknowledged that people with negative views of services could be less likely to participate in research, thereby skewing this finding. Nevertheless, the spousal carers that took part in these interviews tended to present more negative views of services than the men with dementia. This indicates that there are particular factors or pressures that prompted such a perspective of positivity from these men.



For men with dementia the social contact offered by professionals and services was seen as particularly useful. For example, David spoke positively about his relationship with the community-based health professional who visits regularly:

She bowls in, sits down. She asks 'how's things been, how are you doing?' And then she'll get her book out and see what I can remember. I enjoy her company because she is so friendly.  
(David)

Philip also states that he enjoys the experience of mixing with others at a day centre. Engaging in humorous exchanges with other people is a key element of this experience:

There's always somebody that comes and has a little rattle to you and you can take the mickey out of them and they take the mickey out of you. And it keeps you going. If you didn't have somebody giving you a little jab there and a little jab there you'd be bored.  
(Philip)

These perspectives show the advantages of engaging with services, particularly the social connections that this affords. This is not simply a matter of receiving assistance: Philip's account for example shows how he is able to offer a positive social contribution within the support setting. He is taking an active social role rather than simply being a passive member of the group. It could potentially be the case, however, that other factors shape such an expressed acceptance of services: a desire to avoid negatively affecting their partner (see also Charmaz, 1983) could mean that men with dementia are less likely to resist attending services, or be critical of these services. When discussing his attendance at a woodwork group, Oliver shifts the focus from his preferences to acknowledging the break that this affords his partner. In addition, the practical work he is undertaking at this group can meet her request for a particular item for the home. Oliver is thus protecting his partner from the requirement to care for him, while also investing his engagement with services with purposeful activity:

It's something to do. It gives her a bit of a rest from me. She wanted a birdhouse, a bird table, so that's what she's ordered. She wants to get all the robins and things.

(*Oliver*)

A concern is stated by David when he contemplates the future possibility of attending a support group. He alludes to a reluctance to attend such a support, as a consequence of attendees residing in an older age group to him:

*[The health professional]* did say the opportunity was there for me to go, but I sort of felt that I'm more in control and I don't know if I want to go and be with people who were fairly aged or whatever.

(*David*)

When following up this point in response to a question, however, David adjusts his perspective to asserting that he would be able to manage in such a situation:

*Interviewer:* If you did think of accessing a group, would you prefer it to be for younger people?

*David:* I don't think it would bother me to be honest with you in a group. I can mix with people. I see enough people at cricket and things like that. An awful lot of people. I'm sure I could mix and fit in with that sort of situation if it arose. If [*health professional*] came to me and said 'will you come along and help?' or something like that, with various people who are there in a worse state than I am. As of yet, it hasn't got that way.

(*David*)

David intimates that he would prefer not to attend a support group with older people but then adjusts his perspective to indicate that he would be able to manage in such a setting. David's revised perspective indicates further factors that might mediate the expression of subjective preferences on professional support. David moves from expressing an opinion based on one vantage point (feeling in control and a resistance to being with people who are 'fairly aged') to asserting his ability to mix with people of different ages and backgrounds. The direct question from the interviewer leads to a shift in orientation with regard to attending the group, while the appeal to coping and control is sustained. Building upon the discussion of social contribution and helping others above, acknowledging a need for help could undermine a positive sense of masculine self-sufficiency and resilience: "being a patient contradicts the very definitions of manhood, leaving a person vulnerable, weakened and dependent"

(Coston & Kimmel, 2013: 194). Rather than underpinning a strategy of resistance to the available support, it leads to David's assertion of being able to engage with the intervention effectively and help others whose needs are greater. David therefore preserves a positive sense of identity when contemplating support services, by positioning himself as someone who will offer, rather than receive assistance (see also Seymour-Smith, 2010).

It has been noted that seeking support from health professionals is not readily aligned with a strong, self-sufficient masculine identity (Addis & Mahalik, 2003; Davidson, 2013). Receiving care or help is seen as a sign of weakness or vulnerability. The findings above, however, challenge the perspective that masculine identity necessarily leads to a resistance to professional support. The association of dementia with declining cognitive functioning presents a distinctive challenge: inherent within a discussion of services is the implication that men will not have the scope or ability to negotiate their engagement with services comfortably. To *resist* support under such circumstances could be perceived as a sign of weakness or vulnerability. The influence of dementia thus prompts a reorientation of masculine qualities: adopting a stoical position actually leads to men equably accepting the requirement to access support – to the degree that negative perspectives of services are not forthcoming. However, men with dementia also invest the process of accessing support with a sense of purpose to prevent their self-identities being eroded by associations with passivity or infirmity. This is pursued via accounts of active social engagement, practical tasks, or helping others (rather than being helped). In this instance, masculine capability relates to engaging with professional services successfully, rather than self-sufficiently enduring the biological impacts of the condition.

## **Conclusion**

This article has shown how men adopt particular approaches in the endeavour to define and preserve their own personhood, underpinned by an appropriate masculine status. The key strategies identified in this research were: *remaining unmoved, fighting back, emphasising social contributions, and redefining services*. Apparent within these strategies are appeals to resilience, self-sufficiency, enduring agential powers and social contributions.

The presented perspectives demonstrate the endeavour to adopt a position in response to the dementia that enables the men to carry on with their lives in a positive fashion. The negotiation of interpersonal pressures and wider social expectations associated with the condition is required in the pursuit of this goal. Cultural expectations of masculinity, for example, present experiential difficulties for men, with the maintenance of autonomy, control and self-sufficiency rendered challenging by the impacts of dementia. This is in accordance with the wider literature on masculinity and health, but dementia also presents distinctive challenges: its neurodegenerative impacts constitute a direct threat to male identities underpinned by the value placed on independence and instrumental competence. Nevertheless, men also set out to counter negative discourses on illness and dementia that could diminish a positive masculine identity. Men set out to show that they remained 'the same person' despite the impacts of the dementia. This was sometimes achieved by stating a stoical acceptance of their circumstances, but on other occasions a more active and agential means of resistance was asserted. By reorienting their relationship with professional services, men also show how they actively contribute within support settings, thus avoiding being positioned as passive and vulnerable.

This article has asserted the importance of grasping the gendered basis of experience for men with dementia. Overlooking the influence of factors such as gender could lead to the experience of the condition being misconstrued. It is not possible to understand a person's experience if key features of their social location, such as gender, are unheeded. If the complex combination of factors that comprise personhood are understated, then this reduces the scope for the person to be supported in a genuinely human and personal way (Kitwood, 1997). In response to the tendency to marginalise the influence of gender (and homogenise the experience of dementia) it is important to avoid promulgating a binary model that implies men and women have incontrovertibly distinct experiences. The personal strategies noted above are unlikely to be drawn upon exclusively by men. Nevertheless, while straightforward representations and generalisations should be resisted, the findings above underscore that constructions and meanings of masculinity do comprise a central aspect of the identity of men with dementia. Further research can help to advance the appreciation of how gender shapes the experience of dementia for men (and women). The current

tendency within qualitative research to overlook this challenge places inevitable limits on the scope to understand the experience of the condition.

One of the key insights offered in this article relates to how men with dementia could feel pressures, in the endeavour to sustain a positive sense of personhood, to present positive perspectives in relation to accessing services. Dementia policy in England focuses on the aim to assist people to make choices and decisions for themselves with regard to professional support (Department of Health, 2015). The complexity of relational and social conditions however means that making such choices is anything but straightforward. This policy goal accordingly requires greater scrutiny at the interactional level where decisions are expressed, often within triadic settings with partners (or other family members) present alongside the patient and clinician (see also Quinn et al, 2013). Moreover, it is vital to recognise the social and cultural norms that shape the basis of expressed perspectives. The claim is not that social science can aim to discern 'real' subjective preferences that can be disaggregated from their relational and social context. What is being asserted is that a more complete grasp of how preferences are shaped by these contexts can assist with academic and professional understandings of dementia. Greater awareness of the relational and social pressures associated with masculinity will facilitate more effective negotiations with professionals, which can accordingly help men with dementia to articulate their personal preferences and viewpoints.

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