

‘You can get in alright but you can’t get out’

## Social exclusion and men with dementia in nursing homes: insights from a single case study

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### ABSTRACT

The social exclusion of people with dementia is a problem. Older men with dementia in nursing homes are at considerable risk of social exclusion due to factors associated with age, gender, mental health status and this setting. It is not known whether older men in this situation experience it as social exclusion or not. Drawing on a detailed case study from a male participant involved in a larger study on social exclusion, this paper highlights and explores masculine experiences of, and responses to, nursing home life. In this single case study it was found that social exclusion was experienced in an economic, spatial and emotional sense, and the participant aligned himself with other men in the home and masculine behaviours, perhaps to deal with that. Implications for care home practice and research are discussed. The paper concludes that more attention needs to be paid to the influence of gender and, in particular, to the different needs and experiences of older men with dementia in receipt of care generally.

### KEY WORDS

social exclusion  
nursing homes

older men  
masculinity

dementia

Social exclusion is defined by the UK government as: '*an experience characterised by deprivation and the lack of social networks, activities and services that results in a poor quality of life*' (Social Exclusion Unit, 2006: 18). An older person may experience social exclusion due to a combination of several factors including a loss of income and status, and diminishing social networks (Phillipson *et al*, 2004). Someone with dementia may be further excluded due to additional factors, such as the negative impact of a mental health label and lack of appropriate services (Graham *et al*, 2003). An older person with dementia in a care home may experience social exclusion even more acutely due to factors associated with this setting, including it being perceived as a sign of poverty (Golding, 1995); rules and regulations (Peace & Holland, 2001); and being visited less often by friends or relatives (DoH, 2000).

There are currently about 15,700 care homes for older people in the UK offering in the region of 450,000 places (Office of Fair Trading, 2004). Most studies estimate that between 40% and 50% of this client group

have a dementia although, as dementia often goes undiagnosed in care homes, numbers could be as high as 75% (Alzheimer's Society, 2000a). Only a relatively few care homes cater specifically for people with dementia and so most people with a dementia reside in a general care home, where care staff may not have the knowledge, skills and commitment to understand their needs. Those who do live in a specialist nursing home for people with dementia often have to move away from their local community, making it more difficult for families and friends to visit (Wenger *et al*, 2002). There clearly is potential then, for an older person with dementia in a care home to experience social exclusion.

The current state of knowledge about specific factors contributing to the social exclusion and inclusion of older people with dementia in care homes is summarised in **Table 1**.

Despite the extent and nature of knowledge about people with dementia in care homes, there are significant gaps in the literature. First, **Table 1** shows how researchers tend to

**Table 1:** Summary of empirical evidence on factors contributing to social inclusion and exclusion in specific relation to people with dementia in care homes

	Specific factors	Source(s) of evidence
Empirical evidence on social inclusion	Increased opportunities for friendship, meaningful interactions and occupation	McKee <i>et al</i> (1999); Bruce <i>et al</i> (2002); Hubbard <i>et al</i> (2003)
	Ability of individuals to adapt, resist and to negotiate, social roles and control	McColgan (2005); Bruce (2004); Surr (2006)
	Enabling environment: well lit, open plan spaces and corridors, individualised use of assistive technologies; recreation of familiar domestic environments	Kelly (1993); Marshall (2001); Blackman <i>et al</i> (2003); Torrington (2006)
Empirical evidence on social exclusion	Being placed in a care home unnecessarily and/or unwillingly due to lack of resources	Graham <i>et al</i> (2003)
	Restrictive care practices; more common in nursing homes for 'the elderly mentally ill'; malignant social psychology	Tune and Bowie (2000); Kitwood (1997)
	Fear of or actual ostracism by other residents	Meacher (1972); Netten (1993); Peace, Kellaher and Willcocks (1997); Reed (1999); Surr (2006)
	Increased risk of depression, under nourishment and exclusion from primary health care services	Baldwin (2002); Alzheimer's Society (2000b); Schneider <i>et al</i> (2002)
	Disabling environment: noise, over surveillance	Marshall (2001); McColgan, (2005)

investigate care home life from a psychosocial or health perspective and in terms of quality of care issues. No study has investigated the experiences people with dementia have of care home life from a socio-economic perspective and in terms of social exclusion. Second, up until very recently, a person with dementia was regarded, like people with other disabilities, as a '*passive recipient of social forces*' (Hughes & Paterson, 1997, 597) – that is to say, their agency was overlooked. Certainly, little account has been taken of the ability of people with dementia to deal with the poor treatment and exclusion they are reported to face (Kitwood, 1997).

A third gap in the literature is the experience of men. There has been a tendency in dementia studies, as in gerontology generally, to ignore the experiences of men; research has tended to be about 'people with dementia', rendering the particular experiences of men with dementia invisible (Thompson, 1994). Yet men are likely to have very different needs and experiences of care home life than women: they are cast into a '*women's world*' (Peace *et al.*, 1997), where female residents outnumber male residents and where the workforce is predominantly women. Female residents tend to be older and more severely impaired than male residents (Office of Fair Trading, 2004), and men are likely to have very different perceptions from women about 'staying in' and 'being cared for'. Despite these gender differences, very little is known about how men with dementia feel about living in a nursing home. Therefore, the central aim of this paper is to explore how men with dementia experience, and deal with, nursing home life, by drawing on detailed case study material on one man involved in a qualitative study on social exclusion.

## METHODS

The study was qualitative combining a phenomenological methodology with an ethnographic type approach (Maggs-Rapport, 2000). The convenience sample of four care homes taking part in this study on social exclusion were among eight care settings participating in a larger research project examining the balancing of rights and risks for people with dementia in residential settings, and included two general care homes where

people with and without dementia resided, one specialist dementia care home and a specialist dementia care wing of a nursing home. They were located across the south east of England. From the participants in the larger study on balancing rights and risks, the participants in this study on social exclusion were selected.

Participants were chosen for this study using a purposive sampling approach, on the basis of participating in the larger study, consenting to being interviewed and being verbally articulate enough to talk about their experiences. Twelve residents with a dementia diagnosis were included in this study; 10 participants were female and they ranged from 68 to 91 years old at the outset of the study. Ethical approval to conduct the study was given by the appropriate local research ethics committees in south-east England. Ethical issues encountered when planning and conducting this study, including gaining informed consent, are discussed elsewhere (Bartlett & Martin, 2002).

On each visit to a home, a semi-structured interview was conducted and tape recorded, with the permission of participants. Interviews were intended to be broadly about the same topic, namely experiences of care home life. After a general question asking participants how they were, the following questions were asked of participants to help them identify with, and focus on, this topic (Rubin & Rubin, 1995): '*What sort of things do you like to do?*'; '*Is there anything you like to do but can't?*'; '*What do you see as the main restrictions in your life at the moment?*'; and '*What is important to you in your life now?*'. When appropriate, these questions were asked during the course of a recreational activity such as walking around the garden. Between one and four semi-structured interviews were conducted with each participant. These lasted from around 10 to 60 minutes each.

## CASE STUDY

Following this round of data collection, four people were selected for detailed case study work. An individual case study is an established research method in the social and health sciences that allows for in-depth analysis of the relationship between human experience and societal factors (see, for example, Iphofen, 1990; Booth & Booth, 1996; Keady *et al.*, 2004;

Norman *et al.*, 2005). The prime purpose of collecting data using case study is not to generalise, but to provide a platform for theorising about the phenomenon under study (Lewis & Ritchie, 2003). Theorising is best generated from case studies, which use a diverse range of data sources (Blaikie, 1993). So, as well as interview data, a case study typically collects data from documents and observations, from which numerical measurements might also be taken (Gillham, 2000).

The case study method was used in this study to ensure the 'voices of people with dementia' were studied holistically in the context of wider cultural dynamics and practices (Bond & Corner, 2001). In addition, it meant the phenomenon of social exclusion could be explored from opposing, or simply different, perspectives. Participants were chosen for a case study on the basis of consenting to being interviewed again, having a family member and keyworker consenting to being interviewed, and because they had a particular experience of social exclusion. Case studies involved three to five additional unstructured interviews with the participant, semi-structured interviews with a relative and keyworker, analysis of particular documents and environmental observations.

Unstructured interviews with case study participants were conducted away from the confines of the care home so that a participant might feel less inhibited about talking openly – a strategy suggested by a consultant psychiatrist in the early stages of the study. Semi-structured interviews with relatives were conducted face to face and in their own home. Relatives were asked questions about events leading up to the participant moving into a care home and factors they thought impacted on the participant's ability to participate in everyday life. Semi-structured interviews with keyworkers were conducted during working hours in a private meeting room in the care home; keyworkers were asked to describe the participant's typical day and factors they thought impinged on the participant's ability to participate in everyday life. All interview data were professionally transcribed and inputted onto the qualitative data software programme NUD: IST 4 to facilitate storage, coding and string searches of data (Fielding & Lee, 1998). Private care records were reviewed to gather information about the participant, including

date of birth, date of admission to the home and medical diagnosis, how often it was recorded that a person went out in the past three months and frequency and type of visitor received. Further contextual information about the home, including philosophy of care and services provided, was collected from the home's brochure. Notes from analysis of documents and other field notes were added to the NUD: IST programme to facilitate a framework approach to analysis.

## ANALYSIS

The framework approach to qualitative data analysis is useful for applied research as it aims to define concepts, find associations and provide explanations to inform policy decisions (Ritchie & Spencer, 1994). It was adapted for this study to give insights into experiences of social exclusion within care homes for older people. There are five stages to a framework approach to data analysis: familiarisation or immersion in the data set; identifying a thematic framework; indexing; charting; and mapping and interpretation (Ritchie & Spencer, 1994). These stages were followed in this study.

During the initial familiarisation stage in this study important or substantive comments relating to social exclusion and inclusion were highlighted, including what people with dementia said they enjoyed doing, what participants felt they could do, and why participants thought they were, or felt, unable to do things. This stage was guided by the literature on social exclusion and led to an '*initial intuitive analysis*' of the data (Miles & Huberman, 1994). The next stage involved 'lifting' this coded data from its original context, indexing and organising it, as a chart, according to certain themes or dimensions of social exclusion. A total of three charts were generated for this study: chart one indexed types and levels of resources including economic, material and emotional resources; chart two indexed types and levels of participation, including social, political and occupational activities; and chart three indexed restrictions including, structural, cultural and internal/bodily restrictions. Having reduced and simplified the data set, a pattern and connection between them was found: participants experienced social exclusion and used strategies to deal with this.

## INTRODUCING MR BROWN

The case study to be outlined – Mr Brown – resided in the specialist dementia care wing of a larger nursing home involved in this study. Mr Brown was selected as a case study participant because he had been excluded from a local authority home in his home town and admitted to the specialist dementia care wing of a larger nursing home 10 miles away due to his ‘wandering behaviour’. The home was visited five times between March 2001 and March 2002, and approximately eight hours was spent collecting data on Mr Brown. This case study is presented and discussed in detail here to examine the influence of gender on experiences of, and responses to, social exclusion.

Mr Brown was 84 years old at the time of the study and had a diagnosis of Alzheimer’s disease recorded in his care records. He was a widower of two years with a son from his first marriage and stepdaughter from his second marriage. Prior to the onset of Alzheimer’s, Mr Brown said he enjoyed gardening and going out for a drink with one or two close friends. Mr Brown spent all his life in the same small English town. He said he left school at 14 having not learnt how to read and write and had spent all his working life on the assembly line of the same car factory.

According to his stepdaughter, Mr Brown lived successfully on his own for two years following the death of his wife. She became increasingly concerned about her father’s mental health and ability to look after himself when he started to telephone her in the middle of the night to ask her things that she knew he already knew. A social worker became involved and as his confused state worsened, Mr Brown was eventually admitted to a local authority residential home. Mr Brown was transferred to a psychiatric assessment unit quite soon after his admission because he kept leaving the premises and his safety was considered at risk. Following a short stay in hospital, Mr Brown was admitted to the specialist wing of a nursing home approximately 10 miles away.

He had lived in the specialist dementia care nursing home for five months at the time of the study. His stepdaughter said she visited him once a week although, because she did not

drive, she was dependent on other people to take her, she said: *‘I don’t drive unfortunately. I wish I did. So I have to wait for someone to take me’*. According to his care records, Mr Brown had been visited by a family member 21 times since his admission. His stepdaughter mentioned that one of his close friends had visited him once, but because Mr Brown did not recognise him and his friend was upset by this, he did not visit him again. Other external contacts recorded in Mr Brown’s care records included a visit by his general practitioner and optician in the past three months and three trips out: twice on an escorted walk and once to the dentist.

## RESULTS

In this single case study, the finding was that Mr Brown experienced social exclusion and sought to maintain his masculinity in different ways, perhaps to deal with it.

## EXPERIENCES OF SOCIAL EXCLUSION

A recurrent pattern in case study material pertaining to Mr Brown was how conscious he was of exclusionary processes. For instance, something he said after I told him that I would be visiting a gentleman who lived in a sheltered housing scheme suggested he experienced social exclusion in an economic sense. He said, *‘I bet he has got a bob or two more than we’ve got’*. Mr Brown quite rightly perceived that someone in a sheltered housing scheme would have more disposable income than him (Joseph Rowntree Foundation, 2000). Not having enough money was something Mr Brown was used to as, in another conversation, he said: *‘if they give you an extra couple of quid they take it off you in the long run’*, and indeed felt that was what was happening in the nursing home, as he went on to say: *‘(care staff) don’t seem to want to talk to you anyhow, or something like that – once they have got their money they are happy’*. Mr Brown seemed to feel his relationship with the nursing home was essentially an economic one.

Having money was clearly important to Mr Brown. His stepdaughter mentioned he once asked her for money, she said that he said: *‘I have got no money in my pocket... I need*

two or three pound just in case'. In addition, Mr Brown said in one of his interviews how difficult it was to get money: *'everybody wants an extra couple of quid but it is a job to get it. It's a hard life'*. Having worked hard all his life, Mr Brown still experienced everyday life as a toil: *'I was supposed to have retired a long time ago but I can't leave it somehow... I get up in the morning and go to work'*. Despite his age and declining health, Mr Brown still felt the need to be working and earning money. Mr Brown went on to say: *'I am on the sick list now as a matter of fact'*, illustrating how aware he actually was of his own ill health, and also how he still felt in transition from work to retirement.

Other data indicated that Mr Brown experienced social exclusion in a spatial sense. For instance, in response to a question about how he found living in the nursing home, he said: *'you can get in alright but you can't get out'*. He was aware of being interned. Mr Brown's room was on the ground floor immediately adjacent to the front door; in common with other nursing homes the front door would only allow people to exit once a number had been entered onto a keypad. At one point during the interview Mr Brown explained why he thought the front door let people in, but not out. He said: *'well they lock them from the outside door so you can't get out. And they say it is to protect one another, so that one don't clash with the other sort of thing and cause a commotion'*. He was asked to say what he thought about this. He said: *'I think it spoils the job completely'*. Mr Brown sounded aware of being excluded from the outside world, and perhaps felt it was unjustified. Mr Brown also spoke of his experiences of trying to find his way around the building generally:

*'it would be no good me taking you because after about three steps I would be lost and you would have to tell me where to go... All the twisting and twirling round the corners... It is the corners for me, some of them can do it all right of course they can. Once they know where they are going they have got it all mapped out lovely, but not me'*.

Having an upstairs and downstairs and long narrow corridors, not only compounded Mr

Brown's confusion; they also served to remind him of how ineffectual he was in relation to others (who could find their way around).

Other data suggested Mr Brown experienced social exclusion in an emotional sense. For example, according to his care records, Mr Brown would occasionally get upset: a 'crying spell' was noted in his care records a few days after a case review that he attended, and his stepdaughter said: *'he does occasionally (phone) when he gets a bit upset, he has tearful days, then he will phone me and talk to me for a minute or two and then he is gone. And he will say I am sorry I bothered you'*. Mr Brown occasionally felt sad and sought support from his stepdaughter to help him through that. Although Mr Brown did not speak about getting upset he did say things that suggested he experienced distress. For example, he spoke about how unpleasant it was for him not to be able remember things. He said it was: *'more of a torment I think... That is the thing that gets me I start talking like this and then it goes out of my head. I have a hell of a job to get it back. It is awful really'*. Memory loss clearly bothered Mr Brown.

Further evidence of Mr Brown experiencing social exclusion in an emotional sense came when he spoke about how nervous some other residents made him feel: *'some people are awkward to get on with... they have got different ideas to things that I have'*. His stepdaughter also spoke about his relationship with other residents, and indeed felt her stepfather had deteriorated since his admission to the nursing home, partly because there were so few people in the home whom he could relate to. She said: *'he does talk to one or two but there are not many of them are actually like (my stepfather) in the way of talking'*. She felt he was socially excluded in quite a basic way.

As well as being adversely affected by other residents, Mr Brown seemed excluded on an emotional level by care staff. For instance, despite experiencing periods of distress, when Mr Brown's keyworker was asked to say what he was like generally, she said: *'he's fine, the only thing he does worry about out is he likes to be shaved – he is quite fussy about his shave every day'*. The care worker gave no indication of being aware of his emotional needs. Further evidence of Mr Brown experiencing exclusion in an emotional sense came when someone knocked on his bedroom

door during the interview and I wondered aloud if it might be someone looking for him, and Mr Brown said: *'they would soon find you, but they wouldn't worry about me'*. *'Don't you think they would?'* I asked. *'No, I like to pull their legs about it seems the smart thing to do.'* Mr Brown felt himself to be inferior to a visitor and used humour to deal with that.

## ALIGNING SELF WITH OTHER MEN

Another pattern in case study material pertaining to Mr Brown was the relationship he had with other men in the nursing home. For example, when asked about how he spent his time in the home he said he had been: *'working with the boys'*. *'Work with the boys do you?'* I restated. *'Yes, best we can.'* I then asked him what sort of work he did: *'Just labouring work.'* I asked who else he did that with: *'Three of us together going all round.'* Mr Brown felt he was involved in something worthwhile with the other men in the nursing home on a daily basis. His keyworker confirmed certain elements of this story, although she did not see it in quite the same way, she said: *'He doesn't sit still really. He is up and down wandering about.'*

The relationship Mr Brown had with these men was clearly important. He referred to them again when he recalled what it was like when the care workers invited him to take a bath: *'they will bath you. When that first started it started a lot of chatter I can tell you. It seems to work quite well. The boys come down here and say "oi your turn"'*. Mr Brown engaged in a certain amount of banter with the other men in the care home whenever it was 'his turn' to be bathed. Mr Brown's tendency to make light of being bathed by young women was also remarked upon by his keyworker: *'he will come out and say she tipped water all over me if he has been in the shower. And make a joke of it'*. Mr Brown described the actual experience of being bathed in a similarly comic tone: *'the girls bathed us we had some fun and games then I can tell you'*. Mr Brown was conscious of the fact that he is a man being bathed by woman and joked about it in an attempt perhaps to deal with it.

## ALIGNING SELF WITH MASCULINE BEHAVIOURS

In sociological literature using humour to relieve boredom or deal with embarrassing situations is a masculine behaviour (see, for example, Billig, 2001). Another pattern in Mr Brown's case study data was the humorous side to his behaviour. For example, his keyworker said: *'he is very funny with the other residents and will have a laugh with them'*. She described an incident she recently witnessed in the lounge to give an example:

*'we have got one lady who likes him to help her put her feet up on the stool and he will sit there and he won't do it until she asks him. And he will laugh and she says "it is not funny"'*.

Mr Brown also had some fun with me during an interview when I rather unskilfully asked him if there was anything (else) he liked to do in private. He responded to this with a wry smile and asked: *'What are you thinking of – you can't think of anything can you?'* He knew what I knew – that the question I asked him was inane.

As well as being funny, Mr Brown spoke about characteristically male behaviours. For instance, during one interview he mentioned how much he enjoyed watching different sports on the television in the main lounge. He said: *'I love cricket, I can watch that day and night... I like all games you know and bowls.'* In another, he talked about how much he used to love gardening: *'I think that is one thing I do miss... and digging.'* He went on to say what he grew in his garden: *'everything, you know carrots, spuds, everything that went for a meal'*. While gardening is not necessarily a masculine behaviour, talking about it showed how independent Mr Brown had become as a widower. Mr Brown also spoke about going to the pub: *'I always had a straight pint.'* Indeed, this seemed to be something he missed doing because at the end of our first interview after I asked if I could come and talk to him again Mr Brown said: *'I could stay and talk to you all day and go to the pub and have a pint and you have a... whatever, what do you drink?'*

## DISCUSSION

Moving into a care home means different things to different people (Gurney & Means, 1993). In this individual case study it was experienced as social exclusion in an economic, spatial and emotional sense. This 84-year-old widower aligned himself with other men in the nursing home and masculine behaviours, possibly to deal with the social exclusion he experienced.

These results should be considered in conjunction with at least two limitations. First, interpretations of data were never discussed or verified with participants. It is recognised that men and women with dementia particularly should, whenever possible, be involved in every stage of the research process, especially data analysis, to avoid any misrepresentation of their experiences. Second, this paper only focuses upon the influence of gender. Clearly other social divisions (such as class) would have influenced this man's experiences of, and ability to deal with, social exclusion. Taking different societal factors into account is the next step in dementia care and research (Cantley & Bowes, 2004; Hulko, 2002).

Despite these limitations, the study raises several challenges for research and practice. In the first instance, results suggest that greater attention needs to be paid to social exclusion as experienced by people with dementia in care homes. In other studies of social exclusion, it is experienced by people with mental health problems as either discrimination or social isolation or both (MIND, 1999; O'Connor & Lewis, 1999). Residing in a secure nursing home, Mr Brown experienced social exclusion as deprivation in several senses – economic, spatial and emotional. He was aware of his lack of economic power, of being locked in and not being able to exit or find his way around the building, and was troubled by his poor memory and certain other people in the home. The fact that he was a relatively physically fit and articulate man living among quite dependent and inarticulate women may well have compounded his sense of social exclusion.

The results of this study also indicate the importance of gender analysis. According to the literature, it is important to analyse gender in terms of how masculinity (and femininity) are constructed (Edley & Wetherell, 1996). In this single case study, masculinity was

constructed primarily within Mr Brown's relationships with different people. For instance, a traditional masculine working identity was cultivated in Mr Brown's accounts of how he related to other men in the home as: '*working with the boys*' (Gradman, 1994) and a certain degree of manliness came across in his account of being bathed by younger women – '*oi, your turn*', he said. The relationship with his stepdaughter revealed other masculine attributes. Fatherly feelings of affection and protection (Thompson, 1994) were evident in the telephone relationship he was reported to have with his stepdaughter – he valued her support when he was upset, but phoned her back to say he was sorry showing he cared for her. In addition, the belief that '*all men do is shave*' is a gendered one as it does not take seriously the pain and anguish that men experience (Bendelow, 2000: 107). Clearly, future research into care home life needs to explore how masculinity takes its shape and is maintained in such a female environment. Practitioners and policy-makers would then be in a better position to understand and meet the needs of older men with dementia.

According to James and Sabin (2002), people with dementia use the same strategies to deal with the situations they face as they have used throughout their life. Having worked in a car factory all his working life, Mr Brown may well have used humour to alleviate boredom on the factory floor, and in the nursing home used it to make everyday life bearable, as the ability to produce a laugh was clearly the characteristic that defined Mr Brown's membership to the resident group – it '*summed him up*' as a man (Collinson, 1998: 164). The use of humour by men and women with dementia is under theorised in the literature; when it is discussed it tends to be seen as an indicator of well-being rather than as performing a social function (see, for example, Killick & Allen, 2001). Results from this study would suggest that further research is needed into the role of humour in dealing with social exclusion.

Finally, the results of this study indicate that a fundamental change is needed in dementia care research and practice. More attention needs to be paid to the influence of gender, and in particular, to the different needs and experiences of older men.



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