

## **Title: Experiences of rural life among community-dwelling older men with dementia and their implications for social inclusion**

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### **Abstract:**

Current international dementia care policies focus on creating 'dementia-friendly' communities that aim to support the social inclusion of people with dementia. Although it is known that the geo-socio-cultural rural environment can impact on the experiences of people living with dementia, this can be overlooked when exploring and implementing social inclusion policies. This paper addresses an important gap in the literature by exploring the perceptions of daily life for older men (65+ years) living with dementia in three rural areas of England. Open interviews were conducted with 17 rural-dwelling

older men with dementia and the data elicited were analysed thematically to construct two higher order themes. The first focussed on '*Cracking on with life in a rural idyll*' and highlighted the benefits of rural living including the pleasant, natural environment, supportive informal networks and some accessible formal dementia support. The second presented '*A challenge to the idyll*' and outlined difficulties the men faced including a lack of dementia awareness amongst their family and the wider rural community as well as the physical and internal motivational barriers associated with the rural landscape and their dementia. The findings were interpreted through a lens of social inclusion and demonstrated how the geo-socio-cultural rural environment both enabled and inhibited facets of the men's experiences of life in their communities. Based on these findings, the paper offers recommendations for practitioners, researchers and policy makers wishing to promote social inclusion in rural-dwelling older men living with dementia.

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## **Introduction**

Dementia is considered a social disability that may detrimentally impact on a person's life (Bartlett and O'Connor, 2010). Drawing on the social model of disability (Harley, Mpofu, Scanlan, Umeasiegbu, and Mpofu, 2015), researchers have highlighted how social structures (e.g. lack of dementia services or poor diagnosis rates), 'discursive factors' (e.g. stigmatisation of dementia), as well as neurological difficulties (e.g. memory loss, communication and navigational problems) can socially exclude people with dementia. With the global numbers of people with dementia set to increase to 131.5 million by 2050 (ADI, 2015), and the promise of a cure still a distant realisation, international policy directives have sought to better understand how to support people to live well with the condition. Unfortunately, to date, these directives as well as research, often neglect the geo-socio-cultural rural environment and how these interplay with people's experiences of living with dementia (Clarke and Bailey, 2016; Innes and Sherlock, 2004). This paper addresses this gap by seeking to answer the research

question: *What are the experiences of living with dementia for community-dwelling older men in rural England?*

When interpreting the findings, this paper draws on the concept of social inclusion. As such, this introduction will briefly discuss why social inclusion has been chosen and how it has been operationalised within the current study before outlining previous research that has sought to examine social inclusion within a rural context as well as within the context of older men living with dementia.

### **Social inclusion:**

'Social inclusion' is a widely used concept within global political discourse (Taket et al., 2014) and has been a key influencer for promoting the rights of people with physical and intellectual disabilities (UN, 2008). Within the dementia field, the concept of social inclusion has underpinned many of the policies and initiatives that have sought to enhance the well-being of people with dementia and their care partners. One such policy is 'dementia-friendly' communities (Alzheimer Disease International, 2017). These aim to ensure: *"...people will be aware of and understand dementia, and people with dementia will feel included and involved, and have choice and control over their day-to-day lives"* (Alzheimer's Society, 2013, page 10).

As such, adopting a lens of social inclusion for the present study appears to be a prudent choice given its influence within some political discourses.

When conducting research on 'social inclusion,' there is often a lack of consensus on what it constitutes (Davey and Gordon, 2017; Taket et al, 2014); thereby influencing how it is communicated as well as how it can be measured (Simplican, Leader, Kosciulek, and Leahy, 2015). As such, to operationalise social inclusion for the present study a succinct review of the disability and dementia literature was undertaken (see Hicks, 2016). This emphasised the need to understand social inclusion as a dynamic **process** rather than a static outcome, whereby people with dementia have the economic and material means to be included within all aspects of their communities as well as the agency and unconditional opportunity to access, participate in, and personally grow from, social and cultural experiences and inter-personal relationships that are meaningful to them and where they feel valued.

## **Living with dementia in a rural environment**

Dementia policy and research on social inclusion has typically reflected the experiences and needs of an urban ageing population (Clarke and Bailey, 2016); although in the UK there is some evidence of change with the recent move to create 'dementia-friendly' rural communities (Alzheimer's Society, 2018). This is a particularly pertinent challenge to address given that internationally, rural areas will continue to have higher proportions of older people when compared to urban areas (Menec et al., 2015) who are likely to be at greater risk of dementia given the positive correlations with age (Stephan and Brayne, 2014). Consequently, there is a need to better understand the interplay between dementia and rurality and its influence on social inclusion.

Previous accounts of people living with dementia and their care partners in rural areas have demonstrated the power of these communities to both promote and hinder their social inclusion. People with dementia and their care partners in rural Canada (Forbes et al., 2011) and Scotland (Blackstock, Innes, Cox, Smith, and Mason, 2006) drew from the 'Rural Idyll' narrative to discuss personal relationships that facilitated service access and enhanced individualised care. This 'Idyll' portrays a positive, healthy life for older people, where they are free from crime, connected to nature, with strong support networks and a low demand for external services (Menec et al, 2011). Forbes et al., (2011) and Blackstock et al., (2006) also outlined people's strong connection with place and a sense of self-sufficiency, although on occasions this was juxtaposed to their particular situation, with participants discussing cases of stigma and isolation. Other research shows how rural interconnectedness and familiarity can provide safety and a sense of connection for people with dementia (Clarke and Bailey, 2016); particularly when the community is aware of the person prior to their diagnosis (Innes, Blackstock, Mason, Smith and Cox, 2005). However, as Forbes et al (2011) note, there is a tendency for friends and neighbours to withdraw support over time as the symptoms progress. Furthermore, Clarke and Bailey (2016) discuss how this sense of familiarity can lead people with dementia to withdraw from the rural community due to feelings of embarrassment and a belief that their standing has been compromised; highlighting their agency in their experience of social inclusion (Bartlett and O'Connor, 2010).

Other research has discussed the interconnectedness of rural communities that enable formal health services to provide accessible support that is appropriate to a person's needs (Wiersma and Denton,

2016) as well as positive social interactions and meaningful activities (Di Gregorio, Ferguson, and, Wiersma, 2015). However this interconnectedness can also lead to a prevalence of dementia stigma that in turn results in a reluctance from people to engage with formal dementia services (Morgan, Semchuk, Stewart, and, D'arcy, 2002; Morgan, Innes, and Kosteniuk, 2011) or disclose their diagnosis to the wider rural community (Innes, Szymczyńska, and Stark, 2014); although Bowes, Dawson, and McCabe (2018) note, that within their rural European test sites, these difficulties may be reducing.

Whilst research provides mixed opinions on the ability of rural communities to uphold social inclusion for people with dementia, it highlights the importance of exploring these experiential accounts so support can be tailored to people's unmet needs. Currently however the experiences of older men with dementia have not been centre stage; a gap this paper seeks to address.

### **Experiences of community-dwelling older men with dementia**

Limited literature focusses on understanding the experiences of social inclusion for community-dwelling older men with dementia. Hulko (2009) has shown that white older men may be more devastated by the on-set of dementia and rely more heavily on the involvement of others to maintain their well-being and inclusion than those who are less socially privileged. Phinney, Dahlke, and Purves (2013) demonstrated that as two community-dwelling men with dementia in Canada became less active and capable they expressed a sense of loss to their masculinities, leading to periods of frustration. As a result they often chose to undertake work-related pursuits and activities that had filled their lives in the past, and regularly required the input of other family members to enable their social inclusion.

However, there still remains a gap in the literature that examines the experiential accounts of older men with dementia as they seek to negotiate their rights for social inclusion within rural communities; something this study will look to address.

## Research Approach

This paper outlines a descriptive qualitative study, situated within a wider project that drew on the principles of Participatory Action Research (Schneider, 2012) to address the issue of social exclusion for rural-dwelling older men with dementia within an English county through a technological initiative (see Hicks, 2016). The data presented below was collected during face-to-face interviews with the men conducted after the initiative had been delivered. Ethical approval for the study was received from the lead author's institution ethics board. The men provided their written informed consent to participate in the wider research project and their on-going verbal consent to undertake the interviews. This was part of the process consent procedure (Dewing, 2008) adopted throughout the study.

### The rural locations

The 2011 Rural-Urban Classification (DEFRA, 2015) was used as a guide to define the rural settlements. This classification divides England into 171,372 Output Areas (OA) with each one being assigned a classification of urban or rural based on whether its centre is within or outside a built up area of greater than 10,000 people, where a rural settlement is considered fewer than 10,000 people. Furthermore, the classification also takes into account dwelling density for every 100m x 100m square, and at various distances around each square, thereby enabling a density profile for each regional setting. Consequently, this results in six rural classification types: Town and fringe (sparse/less sparse), Villages (sparse/less sparse) and Hamlet and isolated dwellings (sparse/less sparse). Three rural areas were selected for the research in consultation with local memory support workers. A multi-site design enabled the findings to be compared across the different rural locations, thus improving the generalisability of the research. Table 1 presents a demographic overview of the rural locations with data gathered from the 2011 Census.

Location One (L1) could be considered a 'bypassed' rural community (Keating, Eales, and Phillips, 2013). It had poor services and transport links, and was suffering from economic depression, with most of the local funding being directed towards an urban conurbation situated nearby. Conversely, Location Two (L2) and Location Three (L3) were more consistent with 'bucolic' rural communities (*ibid*) with good resources and assets that were attracting recent retirees and London second-home

owners. L2 had good transport links to a nearby major urban conurbation whereas L3 was surrounded by rural hamlets and isolated dwellings.

## **Participant recruitment**

A purposive sample of 17 older men who had lived within the chosen rural communities for between 7-83 years (mean 27.53 years), with a mean age of 80.24 years (range 68-90), contributed to the data. All of the men had a formal diagnosis of dementia and had been diagnosed between a year and 12 years previously (mean 5.18 years). They were all able to provide their consent for taking part in the research and no other inclusion/exclusion criteria were imposed for their participation. All participants were recruited through memory support workers and activity leads within the communities as well as recruitment flyers that were distributed in local buildings (churches, pubs, libraries, halls) and in newspapers. A demographic overview of the participants is shown in Table 2.

## **Research methods**

Face-to-face open interviews were conducted during December 2014-January 2015 and digitally audio-recorded. This method is advocated for enabling meaningful insights into the experiences of people with dementia (Murphy, Jordan, Hunter, Cooney, and Casey, 2015). Walking interviews (Phinney, Kelson, Baumbusch, O'Connor, and Purves, 2016) were offered to the men as part of the research, as it was felt this approach would provide an informal, yet empowering opportunity for the men to direct the interview process by leading the interviewer around the areas of interest for them as well as provide natural, physical prompts that may facilitate more insightful discussions. However, due to the adverse weather conditions at the time, the majority of men chose to undertake them in their homes with the exception of Bill (where the researcher accompanied him on his regular evening walk around the local community) and Chris (who walked the researcher around his large garden as they talked). Whilst this may have restricted some of the conversations about the rural landscape, it was important that these wishes were upheld so as to ensure a moral sensitivity (Heggestad, Nortvedt and Slettebø, 2013) to the research participants. In a further attempt to elicit more insightful discussions with the men, all of the interviews were conducted after the lead author had been working alongside them for a period of ten weeks, whilst delivering a male-only technological initiative that was part of a wider study seeking to promote social inclusion in rural-dwelling older men with dementia (Hicks,

Innes and Nyman, 2019). This initiative used gaming technology such as iPads, Nintendo Wii and Microsoft Kinect as a medium to facilitate conversations about the men's lives, interests and aspirations, and through this generate a sense of solidarity amongst the group (including with the lead researcher). As such, by the time the interviews were conducted both the men and the researcher were accustomed to speaking with each other and sharing information about their lives in a reciprocal manner. This ensured a good rapport from the outset, and also enabled the lead researcher to have a better insight into the men's personalities so that he could tailor his interview approach accordingly. For instance, David enjoyed conversations about pubs and sport, whereas Chris preferred gardening and literature, and so many of the opening discussions focussed around these topics, so as to encourage the men to feel relaxed and comfortable speaking before moving into the main formal interview questions. The interview data were also supplemented with reflexive field notes that sought to capture the lead researcher's thoughts and feelings about the interview process and contextualise this within what had already been ascertained about the men lives during the ten week technological initiative. The interview schedule was used flexibly depending on what aspects the men wished to discuss. However, they all aimed to elicit information on how the men felt about living with dementia within their rural area as well as the perceived benefits of rural life and the challenges they encountered. Typical questions included: How do you find living in (*name of location*)? What do you like about it? Are there any challenges you faced? Do you think these experiences have changed since your diagnosis of dementia? Prompts were used throughout the interviews, where appropriate, to gather further insights into the men's experiences such as 'could you elaborate on that?' 'why do you say that?' or 'could you give me an example of that please?' The interviews ranged in length from between 50 minutes to 90 minutes.

## **Data analysis**

Interview recordings were transcribed, anonymised and uploaded on to Nvivo 10 to manage the data analysis process. Pseudonyms preserved individuals' identity. A 6-phase thematic approach (Braun and Clarke 2006) was used to analyse the data. This involved first reviewing all the data to ensure familiarity with it. Following this, an inductive analytical approach was adopted to ensure the initial codes were grounded in the words of the men. The researchers kept an open-mind throughout the coding process and used both semantic and latent coding to identify as many potential



themes/patterns as possible, on occasions placing individual extracts of the data into numerous codes. Elements of the men's discussions that did not necessarily fit with the dominant story that was emerging from the analysis were also coded. Researcher's reflexions and thoughts were included alongside the initial coding process in comment boxes and were used to guide the development and testing of the themes later in the analysis process. Once all of the codes were identified they were labelled with a short description and then organised into theme-piles. At this stage, it proved useful to develop mind-maps that illustrated how the different codes could potentially combine to form an overarching theme and these were used to facilitate discussions between the research team that were focussed on the relationships between the themes and the different levels of themes. Any initial codes that did not seem to fit anywhere were labelled as 'miscellaneous' and then revisited throughout the analysis. As part of the stage 4 process, the research team discussed how the themes sat together meaningfully and whether there was a clear and identifiable distinction between them (Braun and Clarke, 2006). As part of this process, each of the themes were re-read to ensure they formed a coherent pattern, and where applicable certain data extracts were removed and either applied to another theme or discarded from the analysis. Once there was agreement between the research team on the thematic map created, the data set was re-read to allow the coding of any additional data within themes that had been missed in earlier coding stages. At the end of the inductive process a cross case analysis of the themes was conducted to elicit any differences between the three rural locations.

The final themes were shared with the men during a group feedback session in the three rural locations and they confirmed their accuracy.

## **Findings**

Two higher order themes were constructed from the data. The first focussed on '*Cracking on with life in a rural idyll*' and highlighted the pleasant, natural environment and supportive informal networks that accompanied rural living as well as access to some formal dementia services. The second presented '*A challenge to the idyll*' and outlined difficulties the men faced including barriers

associated with the rural landscape and a lack of dementia awareness in their community. These higher order themes demonstrate the opportunities and challenges of remaining socially included and are presented with their sub-themes below.

### **‘Cracking on with life in a rural idyll’**

Most men discussed living well in their rural environment and many perceived that a diagnosis of dementia had made little noticeable difference to their lives. The majority of men spoke stoically about continuing to ‘*crack on with life*’ (Harry, L3) or ‘*making the most of your life*’ (David, L1) despite a diagnosis of dementia.

*‘It can be depressing... There’s no cure...but there is no need to worry because when your number’s up, it’s up. So just enjoy life while you’ve got it, the best you can.’ (Phil, L2)*

Only Doug, who unlike the other men had recently been diagnosed with the condition, discussed difficulties coming to terms with it. He often described his sense of loss and the ‘*burden*’ he perceived he placed on his wife. Interestingly these losses seemed to be focussed on his perceived inability, since the on-set of dementia, to undertake activities that could demonstrate his masculinity.

*‘...Because it’s taking...my life...it was all around activity and sport and running motorcycles and swimming, in one swoop you’ve lost it all without complaint.’ (Doug, L2)*

When describing the positive facets of their rural environment, many of the men drew from the narrative of the ‘Rural Idyll’ focussing on the natural, pleasant environment, the friendly, supportive informal networks and some accessible formal dementia services. These themes were present across all three locations and provided the men a familiar and safe environment where they could live positively.

- A pleasant rural environment

The men indicated that they enjoyed the remote and pleasant rural surroundings, and the tranquillity that accompanied this. This offered them peace and quiet, and for some a sense of connection with nature, both of which were appealing.

*'It's got more life...there's a herd of deer feeding...we get a terrific variety of birds, and the open space. I like that... It's so peaceful.'* (Terry, L2)

In L1, the sea was a particular attraction for men such as Bob who used to be a professional diver and would still regularly go swimming when the weather was warm enough.

These pleasant rural surroundings encouraged the men to go out for walks, and for many this was a favourite activity they engaged in with their care partner. This enabled them to leave the house, to explore and positively interact with the local environment, as well as provided them an opportunity for gentle physical exercise. Bob, Bill and Doug discussed going for walks independently of their care partner as they enjoyed the alone time. As these were familiar and relatively confined settings, the men were able to confidently navigate them. This provided them with a sense of comfort and security and these periods of independence were important for their mood. As Doug highlighted throughout his interview, he enjoyed walking independently through the pleasant rural environment and this activity helped to distract him and lift his spirits when he was despondent about having dementia.

*'Sometimes I say for god's sake...you're nearly 90 and you're still active and you can still get about. Snap out of it!...So I go for a walk; I sometimes go for a walk three times a day.'* (Doug, L2)

This theme highlights how all of the men viewed the rural environment positively, as it offered them a sense of peace and connection with nature as well as a safe space they felt comfortable navigating within. Engaging independently with the pleasant rural environment was particularly important for offering some men a distraction and therapeutic benefits during periods of low emotional well-being.

- Supportive informal networks

Informal networks were those that provided unpaid support and care for the men during their daily lives. The majority of men reported that this informal support was provided by their wives, and consequently the men came to rely on, or *'worship'* (Barry, L2) them. They afforded the men practical support such as driving them to attend activities in the rural location and surrounding areas, as well as emotional support during times of anger, frustration, and despondency. As Bob highlighted:

*'I get ratty sometimes...but Caroline's the one that keeps everything right...She's the best support I could've had.'* (Bob, L1)

Contrary to many of the other men, Bob and Bill discussed having the majority of their family still living close-by. They would often provide informal support and Bob recounted that during the summer the large family barbeques on the beach were a major source of enjoyment for him. This resonates with the concept of a 'bypassed' rural community where strong family networks can persist and provide important sources of informal support (Keating et al, 2013).

These informal networks were appreciated by the men and ensured they felt safe and were enabled to engage in various activities within their rural locations. For instance, David spoke of playing golf with his wife Anita and some of the local residents, and then going for drinks in the pub afterwards. This was something he enjoyed and he was appreciative of people for continuing to include them in these activities.

*"They (local residents) all live in the village. So it's good to catch up, what's happening in the world. I do play golf with a couple of them...try to play once a week... my wife she plays as well. When I say I'm going up she will say 'well can I come?' So we go up to play 2 or 3 holes and then go in the bar. Have a couple of pints and then come home again. It's a good way to spend the morning really!"* (David, L1)

For Jess, who lived alone since the death of his wife and had no family close-by, these close-knit informal rural support networks were essential for ensuring he could socially participate within the area. His friends and ex-work colleagues would often drop in to see him or transport him to various activities when he was unable to drive himself. These networks continued to ensure he remained socially connected, thereby alleviating some of the threat of social isolation.

*"One of my old work colleagues... he just lives down the road. If I need anything he usually sorts out my car when it wants servicing, I don't want to get under the bloody thing anymore!... I also have what I call a 'Do Lady' who I have known for years. She comes in and does the house, you see...she's lovely and she would help with organising things and help me if I needed it."* (Jess, L3)

The informal rural networks also supported Harry to remain economically active and connected within the rural environment, as he spoke at length about helping his friend (a postal worker) to deliver parcels around the surrounding rural villages.

- Formal dementia support

This refers to services and activities that are specifically designed for people with dementia. They are delivered by trained professionals who have knowledge and understanding of working with people with dementia. Within L2 and L3 the men cited a number of structured activities that were available to them such as Day Centres, Coffee mornings, Melodies for Memories/Singing for the Brain (consisted of singing old traditional songs) and lunch clubs. Most of the men accessed these services and they provided them with a welcomed break from their day-to-day routines. Although, it is noteworthy, that on occasions the men also opted against engaging with some of the activities, citing reasons such as: the people running or participating in them; the approach used during the activities; or the activities on offer.

*'Well, you sit in two long rows and you have three balls to roll along and try to get some score. And then they ask questions which might require an answer. It doesn't do much for me.'* (Doug, L2)

This emphasises the men's role as social active agents in determining their social inclusion, as well as the importance of tailoring dementia support services towards the interests of older men with dementia.

In L1 however, the situation was a little different with the men suggesting there was a lack of structured activities and opportunities for social connection with only one Day Centre that the majority of men chose not to regularly access. This was attributed to the location being *'quite deprived'* (Bob, L1) of funding. Whilst this was not a particular issue during the spring and summer months as the men could access more informal activities within their rural location, it became more noticeable in the winter months when the cold inclement weather meant that the men rarely had the opportunity to venture outside and this was *'horrible for my mood'* (Bob, L1).

## **'A challenge to the idyll'**

Despite portraying positive accounts of living within their rural area, the men were also able to perceive the difficulties they encountered. These concerned the challenges they faced to overcome the physical barriers of the rural landscape as they lived with dementia and grew older, and the lack of dementia awareness in their community.

- Inaccessible rural landscape

This theme refers to the physical barriers of the rural landscape that the men found more difficult to navigate as they aged with dementia as well as the motivational challenges or internal barriers they had to overcome before engaging with the rural environment. These factors worked in tandem to ensure the rural landscape became difficult to access for some men; thereby resulting in their social isolation.

The men spoke of difficulties they faced when navigating the rural landscape and accessing activities that they once enjoyed and were central to their identity. This was evident as they aged and their physical capabilities and health deteriorated. For instance, Colin spoke of how he struggled to negotiate the hilly terrain of L3 with his walking stick and Joe discussed how the on-set of diabetes impeded his capability to walk and negotiate the stairs in his tower block. Consequently he spent a lot of the time in his flat, thereby socially isolating himself. Other men discussed activities and interests they used to enjoy participating in but no longer felt able to do so due to the adverse impact of ageing and/or dementia. These included playing golf (Colin, L3), tennis (Chris, L3), motor biking (Doug, L2), and attending a local rambling club (John, L3) or an open air theatre that was often held in the summer (Harry, L3). Even when the men were physically able to access the rural environments, on occasions they chose not to due to a lack of desire. This sense of apathy was partly attributed to difficulties they faced living with dementia.

*'I've found my motivation has deteriorated. I used to want to get on...but I can't do it...it's because you're getting older and therefore your joints don't work so well...you've got to have that real get up and go to get on with it, and at the moment I just don't feel like that. (Phil, L2)*

Terry also acknowledged that his lust for life had deteriorated since his diagnosis. He stated he had lived two lives; the first was prior to dementia and the second he was currently living.

*'I suppose the capacity for life is a lot smaller... Things were bigger before, more things going on. Life was bigger... And a lot more humorous (before dementia). Was in my first life.'* (Terry, L2)

These issues of physical accessibility were exacerbated by a lack of transport options in the rural environments. With the onset of dementia all the men, with the exception of Joe and Jess, had their driving licence revoked. For some this was still sore, and they spoke at length about the injustice they felt.

*'Yeah I had a bit of a bump... and they just rang up and said you can't have that anymore (driving licence)... I was really annoyed... I'm going to speak to someone about that!'* (Harry, L3)

Consequently, the men were reliant on their care partners to drive them to any opportunities for participation within the rural environment. Although buses were available, and some men spoke of using them, only Gordon discussed travelling independently. This meant the men regularly required care partners to accompany them when accessing activities in the rural environment.

This dependency and reliance on their care partner appeared to adversely impact on their social confidence, and consequently many of the men elected to undertake housebound activities. Although their home comforted them, there was an acknowledgment by Doug that this was likely to detrimentally impact on their well-being in the long-term:

*'Because you're familiar with this (the home environment), this is all good times. This wasn't a worry, this was fun, and you're inclined to closet yourself, and of course that's not good.'* (Doug, L2)

This theme demonstrated how the rural landscape became more difficult to navigate as the men aged particularly due to the barriers presented by the rural locations such as a lack of public transport, and also the deteriorating physical conditions of the men. This was exacerbated by some of the men's sense of apathy and lack of lust for life that was attributed in part to their dementia. These factors appeared to interact with each other, meaning that for some men it was easier for them to stay at home and socially isolate themselves, and this had detrimental consequences for their social confidence.

- Lack of dementia awareness

Despite a predominantly friendly atmosphere from people within the rural communities, there were instances described by men in all locations that suggested they found it difficult to gain support from the local community. This was attributed to a lack of dementia awareness that was evident from neighbours, service providers and family members. The men described a 'fear' (Terry, L2) surrounding dementia, ascribed to its 'unseen' nature (Dick, L3). This fear adversely impacted on people's friendliness towards the men and their willingness to engage them.

*'I'm not finding so many as I used to (people to talk to), but that's just the way it rather goes... Yes, and they stay away for a bit, then they come back, and then you see them, oh, hello, how are you? Well, I must go, because...you know, fat lot of good talking to him, he's gone.'*(Simon, L3)

The men also described instances where relatives and family members had 'no time for Dad now!' (Barry, L2) since the on-set of dementia. For Doug, the combination of ageing and his children's lack of dementia awareness left him feeling like he had lost an important connection with them. Losing this status as a father figure was difficult for him to come to terms with.

*Doug: I'm going down to see my son soon... But that's the only time I can see him, they don't visit.*

*I: Why's that do you think?*

*Doug: Well, I think they probably think I'm a bit of a pain in the arse now. I've got another son...I guess he's visited once here...But the truth is that I'm not much company and they remember me as I was when I was teaching them to ride bikes and chasing them across the moor...My daughter hasn't spoken to me for at least four years.'* (Doug, L2)

This quote highlights the importance that Doug placed on his role as a father and the need to have the capabilities to display masculine characteristics. Consequently, with ageing and the onset of dementia, he felt his abilities to undertake these activities diminished, and along with this the respect he received from his children.



Some men reported that a lack of dementia awareness manifested itself in a questioning of the men's opinions and capabilities. For instance, Joe discussed how he had chosen not to reveal his diagnosis to those who lived in his housing block as he believed their misunderstandings of dementia may result in him losing his role as the volunteer maintenance accountant. This is something he enjoyed and it enabled him to contribute to his community. Instead he chose to only tell his family members, although this also had its complications.

*'I get the feeling that people think you're a nutter...Like... sometimes, my son, I think...he, kind of, not looks down on me but I don't think he values my opinion on things, you know?'*  
(Joe, L1)

Jess also described instances where his son questioned his capabilities and consequently excluded him from decisions. He spoke of professionals visiting his house to fix appliances without informing him they were attending. Jess explained that his son had taken it upon himself to arrange the visits without consulting him, as he did not feel he was capable of doing this. Although he had come to terms with this, he expressed his annoyance at the limited input he had in these decisions.

A lack of dementia awareness was reportedly displayed by health professionals within the rural areas. John discussed walking out of the doctor surgery as he felt he was being infantilised whereas David described a difficult visit to a psychologist where he felt they didn't understand him as a person; choosing only to focus on the biomedical aspects of his condition.

*'...that chat with a psychologist. He didn't do me any good at all...some people don't get it do they? They study and study but they never get to understand the people they are dealing with a lot of the time.'* (David, L1)

This was also highlighted by Joe (L1) who discussed *'pestering'* his doctor to fill out the appropriate forms that would ensure he could maintain his driving licence. Although Joe felt the doctor was friendly, it was evident that he did not understand the importance that the driving licence held for his independence and well-being. Consequently, Joe was forced to drive illegally on outdated papers until the doctor had completed the necessary paperwork.

## Discussion

This study of men's experiences of dementia, demonstrates that, in common with previous international research, rurality continues to offer benefits and specific challenges to people with dementia. Currently, although the 'Dementia-Friendly' communities political agenda is being pushed internationally as a means to support the social inclusion of people living with the condition and their care partners, often the concept of the 'community' is poorly defined or applied homogeneously across a variety of settings. Consequently, as evidenced by the growing body of international literature, it does not take into account the nuances of the rural geo-socio-cultural context that can influence people's experiences of living with dementia. Therefore, if this policy agenda is to be continued then it is essential it acknowledges the interplay between different communities, including those in varied rural locations, and the perceived impact on the social inclusion of people affected by dementia; similar to what is currently underway within the UK political arena (Alzheimer's Society, 2018).

Using a social inclusion lens, for the first time, we put centre stage the experiences of older men with dementia and highlight how facets of the rural environment both enabled and hindered their social inclusion. It is important to acknowledge that whilst the men reported on a number of challenges living with dementia in their rural areas, many of these are universal to people with dementia more broadly and not distinctly associated with rural life such as reliance on informal support networks, the loss of friends and the negative experiences associated with the public stigma of dementia.

- Rurality as an enabler for social inclusion

Similar to other research with rural-dwelling older people (Menec et al, 2015) and those with dementia (Blackstock et al, 2006; Forbes et al, 2011), the men drew from the narrative of the 'Rural Idyll' when relaying their experiences, and were generally very positive about their decisions to live within a rural location. This resonates with other research in the UK that demonstrates people with dementia experience a sense of positivity within their rural environments despite any difficulties they may encounter (Clarke and Bailey, 2016). Whilst this stoicism may be a product of the 'stiff upper lip' mentality associated with traditional masculinities (Capstick and Clegg, 2013), it suggests, similar to other research (Wolverson, Clarke, and Moniz-Cook, 2016), that people can live positively with

dementia and this finding is important for challenging a 'tragedy discourse' that can prevail within the academic and wider public literature associated with dementia (McParland, Kelly, and Innes, 2017).

The majority of men were keen to highlight the perceived pleasant and safe rural landscape, and the friendly and supportive informal support they received. These provided the men a sense of familiarity, attachment and security, which are integral to their feelings of social inclusion, and so ensured they could continue to '*crack on with life*' (Harry, L3) in their rural locations. For some men such as Bob, Doug and Bill, the safety they felt within their rural environments, knowing where they were going or that local residents would help out if they got lost, gave them the confidence to undertake walks independently and this was important for raising their spirits when they were feeling dejected. This resonates with the other literature that highlights the therapeutic benefits the natural landscape can provide, particularly when promoting well-being and quality of life in people with dementia (Gilliard and Marshall, 2012).

Across all three rural locations, the men were presented with material opportunities (Ward, 2009) for social inclusion within their environment on an economic, social and cultural level, through either formal dementia services or informal activities. These recreational activities were important for ensuring the men could retain a sense of identity. Often these activities were accessed through the support of the men's care partners, but where this could not occur, then the informal support networks, developed over substantial periods of time (minimum 7 years and maximum 83 years) in the rural communities, were able to mitigate against this. For men such as Jess, who lived alone after his wife died and who had no close familial support, the informal rural networks were invaluable for ensuring he remained socially connected and could attend events within and around the rural location. This demonstrates the power of informal rural support networks for alleviating the risks of social isolation and exclusion that are particularly pertinent for older people (Age UK, 2018).

- Rurality as an inhibitor of social inclusion

Although it was evident the rural environment had the ability to harness the social inclusion of the men, similar to other international studies (Clarke and Bailey, 2016; Forbes et al, 2011) the men were also realists who did not romanticise rural life. They discussed macro and mezzo rural influencers that

worked independently and in conjunction with one another to provide challenges for enacting their social inclusion. This highlights the on-going dynamic process of social inclusion where people can experience positive aspects of inclusion, within their wider experiences of exclusion (Davey and Gordon, 2017). Interestingly, it is important to note that the men did not discuss financial difficulties and appeared to have the economic means to live well with dementia. Based on political definitions of 'social inclusion' that often associate poverty with exclusion (Marston and Dee, 2015), it is likely the participants would have typically been considered a socially included population. However, by exploring their experiential accounts it was evident many of the men faced challenges to their inclusion due to facets of the geo-socio-cultural rural environment. This finding provides support for researchers who have called for broader definitions of 'social inclusion' to be incorporated into the political discourse (Taket et al, 2014) as well as those that have highlighted the need to examine social inclusion across the spectrum of wealth (Marston and Dee, 2015). It also illustrates the need for qualitative research to be undertaken that can provide more nuanced accounts of people's experiences of living with dementia in rural areas

Within all rural areas, the men reported a lack of dementia awareness from community residents, health professionals and their own family members. This resulted in a 'fear' or stigma of dementia that inhibited their ability to maintain or develop more meaningful connections; with men reporting losing long-term friends after their diagnosis or struggling to retain relationships with their younger family members where they were valued and respected. For some men losing their status as the 'father figure' was a particularly galling experience that detrimentally impacted on their well-being. Whilst it was evident that the 'fear' factor of dementia played an important role in this, the issues were further exacerbated by younger family member's decisions to live away from the rural community, particularly in L2 and L3, making it even harder for the men to retain these important familial relationships. The stigma resulted in some men, such as Joe, wearing a '*social mask*' (Davey and Gordon, 2017) when in the community rather than disclosing his dementia diagnosis, or other men delaying accessing dementia services that could support their well-being for fear of what other people would think. These ill-informed perceptions of the men's capabilities also extended to rural health professionals with men such as David and John reporting instances of being 'infantilised' (Kitwood, 1997) or being defined by their condition rather than viewed as a human. These situations highlighted how family members and the rural community, including trained health professionals, inhibited the social rights of the men by

denying them respect and hindering their opportunities to exert control over their own lives. This is consistent with other rural research (Bowes et al, 2018) and the wider literature that reports people with dementia feel they receive less respect post-diagnosis, resulting in a sense of depreciative self-worth (Burgener, Buckwalter, Perkhounkova, and Liu, 2015) and detrimentally impacting on their social inclusion (Cantley and Bowes, 2004; Cook, 2008). Consequently, these findings highlight the importance of enhancing public understanding of dementia to challenge the stigma attached to the condition, particularly within rural areas where it may be more prevalent due to close-knit networks (Bowes et al, 2018; Innes, Cox, Smith, and Mason, 2006). This might be achieved through employing rural-specific public awareness campaigns, community initiatives and healthcare training that draws from a social inclusion or citizenship framework to promote the human rights of people with dementia (Clarke and Bailey, 2016; Kelly and Innes, 2013). The findings also have important implications for social inclusion research more generally, highlighting the need to understand the experiential accounts of people's relationships rather than merely counting the number of reported social connections (Simplican et al, 2015).

The rural landscape also provided challenges for the men to access these informal opportunities for social inclusion. Men such as Joe and Keith reported difficulties navigating the landscape due to their deteriorating physical capabilities and health conditions, resulting in them socially isolating themselves. This resonates with Blackstock et al (2006) who suggest the once picturesque and safe rural environments can become frightening and challenging to traverse as people age; particularly if they experience navigational difficulties associated with dementia. A lack of transport options also exacerbated this issue. The majority of men had their driving licence revoked (except Joe and Jess) and so were now reliant on their care partners to drive. The emphasis that some men placed on losing their licence highlights how integral it was to their sense of social inclusion. This resonates with Coston and Kimmel (2013) who suggest the revocation of the driving licence is felt more by men not only as a practical restraint but also as it symbolises a lessening of their masculinities where autonomy and control are paramount. Within the rural environment where the car is essential for community participation, then this perceived deficiency in both their social inclusion and masculinities will be continually enforced. This finding provides support for the need to enhance public, 'dementia-friendly' transport within rural areas to overcome practical restraints that inhibit social inclusion and to promote agency for people living with dementia.

It is also important to note that the men influenced their own sense of social inclusion as 'active social agents' (Bartlett and O'Connor, 2010). They reported situations where they were apathetic towards participating in the community or attending formal activities as they did not appeal to them.

Consequently, there is a need to better understand how community-based rural dementia activities can be tailored towards the interests of older men with dementia and re-invigorate their lust for life. It is likely this will be achieved through examining the 'active mechanisms' (Dugmore, Orrell, and Spector, 2015) that can appeal to and promote the social inclusion of older men with dementia (Hicks, Innes, and Nyman, 2019).

### **Limitations of the study and areas for future research**

This research focussed on older men who were predominantly White British and had moved to the rural location before their diagnosis. Future research could consider exploring the experiences of more ethnically diverse older men and people with dementia who have recently moved to their rural locations, who may find these rural networks difficult to penetrate (Blackstock et al, 2006).

Furthermore, although not the focus of this study, it is important to note that masculinities continue to influence the experiences of men with dementia (Sandberg, 2018). For instance, men such as Doug who clearly aligned with traditional performative masculinities that favoured strength and bravery, and felt that these gained him respect from his children, viewed the onset of dementia and ageing as something that undermined his masculinity and his status as head of the household. Consequently, this is why he perceived that his children no longer took the time to visit him, and this detrimentally impacted on his sense of identity and well-being. Whilst this paper was concerned more with the influence of rurality on social inclusion, it is important that future research seeks to adopt a more nuanced approach and examine how these diverse masculinities operate within a rural environment to influence the lives and identities of older men with dementia.

### **Conclusion**

This study is the first to situate the voices of older men with dementia at the forefront of the research to examine their lived experiences of rural life and its role in enabling and hindering their social inclusion. In doing so, it highlights the importance for researchers, practitioners and policy makers to attend to the voices of older men with dementia within diverse rural communities to understand how

they can best promote their social inclusion and succeed in their quest to enable 'dementia-friendly' rural communities.

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**Table 1: Demographic data for the three rural locations**

<b>Demographic data</b>	<b>Location One (L1)</b>	<b>Location Two (L2)</b>	<b>Location Three (L3)</b>
RUC	Rural town/fringe (non-sparse)	Rural town/fringe (non-sparse)	Rural town/fringe (non-sparse)
Population	4,013	5,496	7,314
Males	2,254 (56%)	2,563 (47%)	3,488 (48%)
Population over 65	577 (14% with 7% males)	1,504 (27% with 11.5% males)	1,613 (22% with 8.5% males)
Median age	40	50	43
Population density per hectare	12	8.6	16.3
Day to day activities limited	21.8%	21.5%	17.6%
Health very good/good	78.2%	78.9%	82.4%
Health very bad/bad	6.2%	6%	4.2%
White British	89.8%	96.3%	93.3%
Economically active (% of those aged 16-74)	62.7%	67.9%	73.8%
High skill occupation	28%	32.8%	32.9%
Low skill occupation	28.2%	21.6%	23.8%

Notes: RUC: The Rural-Urban Classification (DEFRA, 2013).

**Table 2: Demographic details of the men**

Location	Pseudonym	Age	Years since diagnosis	Years in residence
L1	David	68	2	20
	Joe	71	4	25
	Bill	87	2	23
	Bob	75	10	75
L2	Phil	77	7	12
	Doug	90	1	10
	Terry	82	2	19
	Norman	83	3	83
	Barry	84	3	15
L3	Jess	86	5	52
	Gordon	76	2	11
	Dick	90	7	28
	Colin	79	7	32
	John	84	11	7
	Harry	70	7	25
	Chris	77	12	20
	Simon	85	3	11

Notes: all men were White British ethnicity

