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Narrative Citizenship, Resilience and Inclusion with Dementia: On the Inside or On the Outside of Physical and Social Places

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Narrative Citizenship, Resilience and Inclusion with Dementia: On the Inside or On the Outside of Physical and Social Places

Abstract

There has been little research that addresses the importance of place in enabling resilience and citizenship – most to date focussing on these as a characteristic of the individual.

This paper reports on findings from a qualitative study that aimed to explore the everyday experiences of living with dementia within rural and semi-urban communities. Data collection included a sequence of four research diaries and interviews with 13 families living at home with dementia and interviews with service providers and commissioners (a total of 57 diaries, 69 interviews with people living with dementia and 6 interviews with service providers and commissioners). Key themes identified included: Others Knowing and Responding; Socially Withdrawing and Feeling Excluded; Sustaining and Changing Activities; Belonging and Estrangement from Place; Engaging Services and Supports.

The study found that familiarity with people and place can be supportive, and these factors support a narrative citizenship in which people can tell a story of inclusion and feeling on the inside. However, this familiarity with place may also create a social barrier and a sense of estrangement, or being on the outside. Narrative citizenship allows us to explore how people with dementia position themselves in relation to others and in so doing, negotiate their own and other's understandings of dementia. It also allows for people to tell stories about themselves in relation to their sense of belonging in a social and physical place, which augment the personal and political approaches to citizenship and thus offers an approach that enhances individualised yet collective understandings of living with dementia.

Key words: resilience, place, citizenship, dementia

Word count (excluding title, references, table and abstract): 7,839

Narrative Citizenship, Resilience and Inclusion with Dementia: On the Inside or On the Outside of Physical and Social Places

Background

People with dementia and their family members seek to preserve autonomy and identity as key features of citizenship (Clarke *et al.*, 2010), and this has been equated with resilience (Braudy-Harris, 2008; Hildon *et al.*, 2008; Low, Keating & Gao, 2009; Windle, 2011). There is increasing attention to ways in which resilience can contribute to a quality of life for people with dementia, and indeed older people in general (Elmore *et al.*, 2011; Nygren *et al.*, 2005). Windle (2011) defines resilience as ‘the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma’ (p. 152). Older people, it is argued, use a range of strategies to protect their self-esteem and well-being (Collins & Smyer, 2005) and deploy different sources of strength to adapt constructively to stressful life events (Janssen, van Regenmortel & Abma, 2011). Largely, the work on resilience has focussed on individual characteristics and the individual’s ability to mobilise assets. This focus is of particular significance in relation to people with dementia, who may not have (or may not be ascribed by others) the capacity to make and enact decisions that enhance resilience (Clarke *et al.*, 2010). However the focus on the individual has been criticised for obfuscating wider political and social influences. For example, Baldwin (2008) suggests that our personal narrative, the stories we tell about ourselves, are woven with strands of these wider influences: ‘the personal, interpersonal and the institutional/structural are inter-related through the stories we tell and are told about us, whether by individuals or collectivities’ (p. 224). Baldwin (2008) speaks of ‘narrative citizenship’ in that people with dementia position themselves in relation to others, and in so doing have to negotiate their own and other’s understandings of dementia. They also tell stories about themselves in relation to their sense of belonging in a social and physical place.

Bartlett and O’Connor (2010) expand citizenship to include ‘social practice’ on the basis of Prior *et al.*’s work in which ‘individuals relate to other people, their communities and the state’ (Prior, Stewart & Walsh, 1995) and Barnes, Auburn and Lea’s (2004) notion of

‘everyday talk and actions’. Marshall and Tibbs (2006) assert that a citizen approach to living with dementia needs to be based on reciprocity so that the focus is not just on the resources required by someone but also includes consideration of someone’s strengths and assets. However, despite the interest in citizen approaches (Bartlett & O’Connor 2007), few studies take full account of the wider context in which experiences are taking place (e.g., Gilliard *et al.* 2005; McCabe, 2006; Proctor, 2001). There are indeed significant challenges for people with dementia in continuing to experience citizenship within their community. In the UK, dementia is estimated to affect 800,000 people with 670,000 family and friends acting as primary carers, and the number of people diagnosed with dementia is predicted to increase to 1.7million by 2050 (Alzheimer Society, 2012). A significant proportion of people with dementia feel that there are shortfalls in their inclusion in their community – the Alzheimer Society (2012) reported a YouGov survey of people living with dementia which found that 22% did not feel part of their community and 38%only sometimes felt part of their community, 61% felt that their community does not understand their condition and 71% would like their community to understand how to help them live well. Members of the general public similarly recognised a lack of inclusion in their community for people with dementia, with 60% indicating that inclusion was fairly, or very, bad (Alzheimer Society, 2012). The response to the lack of inclusion of people with dementia has been significant, including the ‘Dementia Friends’ training programme to increase awareness and understanding of dementia, dementia friendly cities initiatives, and a dementia education pioneer programme with schools (Alzheimer Society, 2012). Public Health England identified dementia as one of its seven high level priorities for 2013/14 (Public Health England, 2013) in line with the WHO statement that dementia is a key public health priority (World Health Organization & Alzheimer’s Disease International, 2012).

The resilience of people to situations that may otherwise be overwhelming to their sense of themselves, is to be celebrated and requires health and social care practitioners to consider *both* risk and resilience when they make decisions about services and supports for people living with dementia. More needs to be known about how people living with dementia and the significant people in their lives, define and manage risk and draw on their own resilience to foster well being and a good quality of life. This includes developing a more thorough understanding of ways in which ‘everyday relationships and attachments to, with and

between people and place are significant aspects of how a person living with dementia may or may not continue to affirm their identity' (Bailey *et al.*, 2013 p.398) and how this contributes to understanding people with dementia as citizens. To do this, and drawing on a narrative citizenship approach, this study focuses on sharing and contextualising people's stories and everyday experiences about living with dementia from within individual (personal) and structural (political) contexts.

The Study

The focus of this paper addresses the study's purpose in understanding how people who are living with dementia narrate their everyday lives within individual (personal) and structural (political) contexts.

The study was located in NE England, in an area characterised by rural and semi-urban areas (population density of 63 people per m², with a mixture of very sparsely populated areas, small towns and villages – Northumberland County Council, 2015), with varying difficulties in accessing services, social networks, transport and consequently varying opportunities to 'age in place' (e.g. Wiles *et al.*, 2011). Ethical approval was secured from Northumbria University and the Social Care Research Ethics Committee (Ref: 11/IEC08/0027).

Recruitment

Fifteen GP practices agreed to participate and searched patient databases to identify those who met the inclusion criteria of: capacity to consent or an appropriate consultee, and a diagnosis of dementia that is known to the individual and their relative. GP practices also drew on personal knowledge of individuals to identify those for whom involvement in the research may have been inappropriate (e.g., a recent adverse event such as family bereavement or already involved in other research).

Initial participant contact and information about the study was provided by the GP practice. Expressions of interest were then followed up by the research team, firstly with a telephone call and then a home visit. This visit was to introduce the study and to discuss the

information received from the GP practice. Consent was only sought once the person was clear that they wished to take part in the study. The research involved several points of data collection (as detailed below) and consent was reaffirmed verbally at the beginning of each of these visits. The person with dementia nominated a family member who also received information about the research and provided informed consent to participate.

Thirteen people with dementia were recruited from eight of the participating GP practices. Nine participants lived in rural small towns and villages, and four lived in semi-urban areas. For most, a family member also took part: 11 spouses living with the person with dementia and one daughter-in-law who had daily contact with her mother-in-law but did not live with her. One participant with dementia lived alone with family members very close by but none chose to take part in this study.

Participants had been living with a diagnosis of dementia from one to ten years, with the majority having been diagnosed within the previous two years. Participants had lived in their current home from six to over 50 years. The majority were born locally with extended family in the locality or had moved into the area many decades previously. The participants with dementia were aged from mid 60s to early 90s and were six men and seven women.

Data Collection

The majority of participants were visited at home six times over a 12-month period. As well as the introductory visit, four visits were scheduled to include a recorded interview that focused on different aspects of every day life:

- Interview 1 - daily activities and routines;
- Interview 2 - contacts and connections with family, friends, neighbours, professionals and others;
- Interview 3 - involvement in civic life such as being a member of a local society;
- Interview 4 - ways of continuing personal growth through, for example, sustaining life-long interests or beliefs.

Table One below gives further details of participant interviews.

INSERT TABLE ONE HERE

During each visit, the family member was also invited to give a separate interview although a third of the households chose to be interviewed jointly. In total, 89 interviews were conducted with participants who were living with dementia (either with a diagnosis themselves or as a family member). All interview data were audio-recorded.

At the end of each visit, short field notes captured 'threads' between visits, as well as new developments and general household dynamics. The nature of a series of interviews allowed previous interviews to influence the ways in which the questions were asked and optimised the opportunity to explore any issues from the previous interview, and those with other people, so that the interviews became a linked series with each family and also had cross-links of ideas between different families. For example, there was considerable discussion about balancing 'risky' behaviour with trying to maintain some sense of autonomy and independence, both for the person with dementia and for the family member. The sharing of information unfolded over the course of the interviews, with time available to develop trust and for the interviewer to develop an understanding of the complexities of living with dementia for each family. For example, Alfred described his guilt at leaving his 88 year old wife Edith (who was diagnosed with dementia three years earlier) alone and in bed at 5am, so that he could do the monthly 'big shop' and be back well in time for her usual 9am awakening. He conceded that he had sometimes returned to anxious neighbours who had found Edith outside and distressed, still in night attire.

Both the person living with dementia and their named family member, were also invited to record a seven-day diary. This was repeated on four occasions. Each diary covered the topic that was then discussed during the subsequent home visit and with permission, framed the recorded interview. Although adding to the overall data volume and rigour of qualitative research (Alaszewski, 2006; Clayton & Thorne, 2000), despite trying to ensure that the diaries were simple to follow yet engaging, they were viewed by many participants to be 'very repetitive', and 'it feels like I'm going through the motions.' Also for some family members, diary completion caused concern: "I kept reminding her but it was no good and when she did get down to it, she kept asking me to do it." Others did complete all their

diaries although they too had found it *'a bit of a chore'*. In total, 57 diaries were completed, varying in content from functional lists (e.g., weekly activities) to descriptive accounts of everyday life. Dementia was only mentioned in relation to specific visits to clinics, hospitals or when the person was faced with change such as *'needing to fill in a DVLA [Driver and Vehicle Licensing Agency] form and waiting to see if the driving license gets renewed'*.

In addition, audio-recorded interviews were also carried out with six stakeholders who were working in the public and charitable sectors and who had input into community supports and services for people living with dementia in the study area. These interviews sought to elicit key informants' perspectives on ways in which service provision promotes resilience and supports the strategies used by people living with dementia, to manage risk. Questions included: 'what are the key enablers/barriers to promoting resilience and improving wellbeing for people living with dementia?'; 'what do you think people living with dementia want from the services you can provide?'; 'where does the responsibility for the management of risk lie and how might this impact on promoting resilience?' and 'are there ways of promoting policy and practice that align self-management with effective models of service provision?'

Data Analysis

The data were qualitative and were analysed using constant thematic comparative analysis (Fram 2013; Thorne 2000). Firstly, each household was analysed as a set of linked interviews. For each household, all diary, interview and field notes were read and the data grouped into common instances (codes) and related instances then grouped into themes. Tensions within these themes were also identified. For example, whilst having lived in a local community for a long time might nurture a strong 'sense of place' and have positive impacts on one participant's quality of life, for another, there may be a sense of 'no longer fitting in' with an acute embarrassment of everyone being aware that the person has in some ways 'changed'. Secondly, themes relating to individual households (their set of linked interviews) were then compared across the other 13 households.

The Findings: On the Inside or On the Outside of Physical and Social Places

The participants narrated their experiences of living with dementia in relation to their individual (personal) and structural (political) contexts of social and physical environments. These narrated experiences are presented around five themes:

1. Others Knowing and Responding
2. Socially Withdrawing and Feeling Excluded
3. Sustaining and Changing Activities
4. Belonging and Estrangement from Place
5. Engaging Services and Supports

There is considerable cross-linkage between these themes as any one theme interacts with the others. Within and between the themes there is a dyadic tension between, for example, feeling socially excluded by other people and self-imposed exclusion from conversation for fear of saying the 'wrong' thing.

Others Knowing and Responding

For some participants, there were anxieties expressed about others' perceptions of people living with dementia. Indeed at times, the social implications of the diagnosis seemed more troublesome than the physical and cognitive symptoms, and family, friends and neighbours were described as struggling to adapt to the diagnosis. There may be some noticeable changes (for example, a person becoming forgetful or a bit 'lost' in a conversation) but participants spoke primarily of being aware of being treated differently. In the following quote, Margaret talks about other people's reactions to her husband Jim.

Margaret - Oh, I think everybody we know – even the neighbours, you know, they'll come in and say hello, but they still don't, you know, treat Jim as if he's normal. You know, they'll talk to me and not Jim really. Don't they, Jim?... But it would be nice if there was more places for - where people with dementia could go, you know, and they were treated - had some sort of quality of life. Because you seem to lose all

your quality of life, once they say you've got dementia. And even, me, I mean, I'm probably not that good with it, because, I mean, you know... You just give up hope I think.

Stakeholders also noted negative public perceptions, which lead to the marginalisation and stigmatisation of people with dementia. A manager of a recently opened day centre, accommodated within extra care housing, commented:

Manager of Day Centre - *People can be so cruel. Anyway, I think I'm trying... I'm starting to break down that resistance, by encouraging them [those living in the extra care housing complex] to come and visit in the Centre. See that we're all human beings. We all have feelings, we all have emotions – we may just have lost one or two marbles, that's all. And I try to integrate as much as I can, but there are those who just don't like us in the building and won't be happy until we're out of the building. And I find that very sad. And upsetting.*

Several of the participants discussed how hard it is to get on with everyday business when others 'just rush at you', 'think you are stupid' or 'want you to do things their way'. There was also acknowledgement and appreciation of those who demonstrated that 'they've got time for you'. In other situations, people made light of their dementia by comparing it to other problems people face ('it's just another thing, like someone being a bit deaf or having to sit') or by using humour to defuse situations ('you can have a laugh'). In the following quote, Mary explores how she feels about other people knowing of her diagnosis and her reluctance to share that information with people at the moment.

Mary - *I would feel, speaking for myself and, being terribly sort of egocentric about it, I would be reluctant to discuss it with other people. I feel slightly embarrassed. I want to get along with it myself. I do the best I can. I do everything I can. And other people's experiences wouldn't help really, you know. It's just sort of, a problem shared is a problem halved for them. And perhaps for me... But... There may be a bit in that, yes. Sorry to be... In a year's time, when things are, you know, not quite the same. Maybe then. But, at the moment, I want to rely on myself.*

These mixed feelings about other people knowing that they had a dementia diagnosis, and perceptions of how people responded to that knowledge, led to changing levels of social engagement.

Socially Withdrawing and Feeling Excluded

People with dementia talked about needing more time to process information and identified how disconcerting, even frightening, it could be to deal with encounters in banks, shops, cafes and everyday spaces. For example, Jane used to work in a senior management role and talks of her uncertainties in communication now and how she is sometimes left feeling excluded:

Jane - People I don't know is difficult. I'm not sure what to say to them... I think that's probably the worst bit. Because I used to be quite a chatterbox.

[Interviewer] And do you know why that is?

Jane - I'm always sure that I've just lost... Lose some words. And sometimes if they ask a question, I'm not sure what the answer is anyway ... If it's going to be somebody talking for a long time I would tell them [that I have memory loss]. And I told a lot of people, you know, all my friends and neighbours. And the people we go to when I get my hair done. I've just got a new girl now. And one of the first things I said... And she was really looking after me and taking me down to this... I thought, "Well I'm not that bad, but never mind."

In the following quote, Jim talks about how he feels dementia affects his communication with his wife and causes him to withdraw from making contributions in social settings:

Jim - ...until this dementia came on. And it's gone all haywire, you know. And we never shouted at each other, but we do now. I'll be honest about it. Which is not very nice for her and it's certainly not nice for me, you know. So, when people come or don't come... Well, and when they come and they're talking, I just sit and listen. I don't involve myself in it. As somebody would say "in case it's wrong". You know. And I don't know where to go from there. But I can just go out and do what I want to

do, but... Sometimes I want to talk to people and so-an-so, so I'll just say "Oh, no. I'll just sit back... And think."

Many of the people with dementia who participated in the study spoke of forgetting words and trains of thought within one-to-one and group conversations. Some suggested that one strategy for coping with this was to withdraw socially because they felt shunned by people: 'Once you say "Oh, he's got dementia..." they just ignore you' (Margaret). This led to feelings of inadequacy and of being 'outside of company' – at times, feeling isolated and lonely and with a diminishing independence.

Dorothy - I think part of Mike's problem is, he used to have quite a lot of interests. I mean, he loved playing indoor bowls, and there was a very good bowling club which he was very involved with. He used to enjoy golf. But I think, because of the memory problems, he finds it more difficult to be involved in those sort of things, so he's just... Well, you've just given them up really, haven't you? Which is a shame - because you enjoyed them so much.

This sense of being 'outside of company' shaped the ways in which people engaged with their former daily activities, sometimes finding ways of sustaining activities that were meaningful to them, but sometimes relinquishing them.

Sustaining and Changing Activities

Participants discussed how living with dementia does bring changes such as forgetfulness or a sense of 'missing something' and this can cause concerns for the person with dementia and others. In particular, there can be anxiety that continuing with past activities (such as going for walks alone) may compromise safety. For example, Jane enjoyed accompanying her husband on local shopping trips or visits to the library or GP. They both recalled the 'horrible panic' that ensued when he left her at a bus stop in the rain (to retrieve an umbrella from their car parked nearby) and she forgot, panicked at his absence and walked away a short distance.

In the following quotes, Sarah and Peter discuss how they seek to continue to do familiar activities.

Sarah - Sometimes it's hard. You're sitting, trying to think, "Well, how on earth do I play bridge?" And you can't work it out. But when you're actually in the situation, it just comes naturally... Fred [husband] is pretty good – he can do most things. I'm getting back onto the cooking again. At least making the lunch and the tea and the breakfast, sort of thing. And I made a whole pile of sandwiches yesterday, which I hadn't done for a long time, because Jack and Oliver [grandchildren] came over for their tea.

Peter - I'm able to get out and about and still do most of the, sort of, jobs that I would normally do around the house – the gardening. Although it's not a huge garden anymore, so there's not much to do. So I'm not really aware of it [dementia] all the time. I'm not aware of it all the time. But at certain times it could be... Well, it's spasmodic, so something could happen and I would forget all about it and... You know, it's gone.... But most of the time I feel okay, and I'm not really aware that I'm losing my memory. I know I'm losing my memory, but I don't feel like it.

This transition of sustaining and changing activities was echoed by a stakeholder, a member of an independent charitable organization who runs weekly crafts and activities sessions for people with dementia and family members.

Member of Independent Charitable Organisation - I think we get people where they are halfway between being able to function perfectly normally in a community setting of any sort – or things they've done before – and people who actually need day care. I think they want to carry on with their hobbies, but they need a little bit of support. Whether it's prompting, whether it's somebody to go at the speed that they want... a bit of reassurance and confidence.

People were experiencing considerable role transition, particularly with close family, as highlighted below by Dorothy whose husband Mike has dementia.

Dorothy - I suppose the biggest change in my life is Mike has always been the head of the family, and has looked after everything from finances to gardening to things that needed doing in the house to holidays to everything. He has always sorted those sort of things out. And I've been very much a sat-at-home mum, really. Raising [children]

and shopping and things like that. And I find it quite difficult now to take on the role that Mike has looked after all of those years. But I find that I'm having to do more and more. And, yes, I do find it difficult, and I suppose that is the biggest change.

Participants with dementia talked extensively about 'filling in the day', not wanting to go to the 'day centre' and curtailing social activities because of now feeling 'awkward' in social situations. In the following quote, Mike spoke of his wife (who cares for him) and his own loss of confidence in doing things that had previously been part of his everyday life.

Mike - Well, I... I think I lost all confidence in many areas that at one time I would have been confident. And whether it's because I'm slow in doing things, or, well, I just can't do things – I'm not sure. But Dorothy has always been a very organised person, let's say... I'll have to be careful how I worded that there. And, yes, I wouldn't say that I'm slapdash but... at all. I don't think I'm as bad as Dorothy thinks I am.

For the significant person in the life of the person with dementia there were mixed opinions about the 'caring' relationship. Participants spoke of changes in their relationship with the person diagnosed with dementia and concerns about the future: *"I honestly don't know what'll happen after I'm not here."* (Roy, whose wife has been living with a dementia diagnosis for about ten years). For others, there seemed to be acceptance of change. For example, Alice spoke of not going out as a couple so much since her husband Robin's dementia diagnosis about two years prior to the study. However she felt that routines were important and twice a week they would take the bus into the city, have a meal or go to the cinema although Robin increasingly found walking difficult: *"So we just walk down the path and then come back and sit on the seat. And [addressed to Robin] you just sit and watch the world go by."*

In describing the ways in which people who have a diagnosis of dementia relate to their family members and activities with their community, they narrated shifts in the nature of their citizenship and the sustaining and changing nature of being within their community.

Belonging and Estrangement from Place

One aspect of these sustained or changed activities is that they took place within the communities in which the participants lived. These physical and social places were ones that participants had long and complex relationships with. Many participants in this study have been living in their communities for many years, as highlighted by Rebecca below.

Rebecca - We were brought up in a house up there, and then we were lucky because we had a bath in the kitchen with a bench across that you lifted up ... And my mam didn't have running hot water, she had the boiler ... and then getting the hot water in the bucket and putting it into the bath and everything. ... And then we moved down here, into number one. And my mam [mother] and dad were there until they died. And then... when I got married I lived in one room in [nearby city] in this house, which ... a lot of people did then, and you had a shared kitchen and that, you know. The public baths were along the road. And then I got number [house number] here, which is round the corner. And my mam rang up and she said, "Ee, there's somebody got... that house has been allocated around the corner, somebody I know." So I said, "You mean - You mean I've got it. You mean I've got it." ... I said, "I've got a house at [village]" [where Rebecca still lives now].

Participants spoke of how this history of living in the same area can be enabling in that there is long standing familiarity with people and within places. This is illustrated in the following quote from Robin:

Robin - We're well-liked and respected in the area because we sort of... My father was only, he was, was it eighteen months [old] when he came here from Cumberland. He had, he worked in the mines. He was a... what do they call it, a... he was...

[Interviewer] Did he cut the coal? Was he a hewer?

Robin - That's exactly what, he was a...no, he was, he was a, a shaft sinker. He used to...

[Interviewer] And that's how you ended up being here all your life?

Robin - Aye [yes].

However such familiarity can also be challenging. Margaret and Jim (who are in their late 70s) have been living in their current home since their marriage 12 years earlier. Margaret had lived in the area for many years, had introduced local friends to Jim and they had enjoyed being sociable. During the interview about social contact, Jim expressed how 'going out' could uncomfortably highlight the loss of himself as others knew him prior to his diagnosis (something he responded to by tending to socially withdraw):

Jim - personally, being honest about it, I try and avoid it [seeing other people], because they say to me "Oh... Oh, you've changed. You sit there and say nothing." Don't they?

Margaret - Yeah.

Jim - You know... Which is quite right, but... I think, I'm trying to come out of it now, whether it's silly or wrong or what, you know... But I am a lot quieter than I was. And I know that. Because I don't want to go out and make an idiot of myself, say something and it's wrong.

Margaret - It's altered your life... Altered his life completely.

Jim - It makes you feel... How can I put it? It makes you feel... You know, Oh, God, has somebody else come and I haven't said anything to them or anything like that, you know. Makes you feel a bit down. You know. And it's... I don't want to ask something and it's crazy, stupid or... Anything like that, you know. And I try to think and... You can't... It just goes off... Off my head.

[Interviewer] Do you tell them "Actually I've got a memory problem"?

Jim - Yeah, I do. Oh, yeah. Yeah. Make sure they know... But, I don't want to live on it. Do you know what I mean? I don't want it to say "Oh... Well, you know very well I've got dementia and I've got so and so" you know, that... "Oh, no. I didn't know that." You know. I'll say "Well, just forget it. I am. And I'll get out of it. Don't worry. Margaret and I are going against it and we're going to win." And that's it. You know. Well, you've got to say something... And I sometimes think, as she said, I worked at [company] and I was a manager... every supplier we had, 500 suppliers, for the lines for what they built... I think I must have known every bugger there.

Participants reflected on how the places that they knew so well brought a sense of continuity and stability for them, but could also be experienced as places that were themselves changing. In the first quote below, Peter talks about the changes within natural rhythms of the days and seasons in the countryside, which brought interest and reassurance. In the second quote, Roy discusses how a place he knows well has changed around him as new houses have been built.

Peter - *I enjoy walking along the beach, though. It's, I don't know, well, it just changes, doesn't it? It changes every day, really. Depending on the tides and the wind and whatever. So it's always, it's always something different. And you never know what's going to be washed up on the beach, you know.*

Roy - *We used to know everybody once over. I don't know. Because there's a lot of people moved in here, you know, into [village]. And I wouldn't know if they lived here or not. If you go into the pub on a Saturday or Sunday – I know them. And that's about as far as it goes, actually. Whereas when I moved here, you got to know everybody round the village. But now there's other houses being built. They've built their own community. And the villages are getting less and less and less, the original villages. And they often get, sort of, left on the side-lines. The new people are taking over, basically.*

John echoed this sense of estrangement from a formerly familiar place too in the following quote, this time ascribing this to changes in his memory rather than the community.

John - *I must have driven these roads many times before. But it's like living in a foreign country. I don't recognise them. And it seems to take an awful long time – a tremendous long time – whereas... Probably in the old days, when I was driving... I didn't take... You know...*

[Interviewer] *Yeah. It didn't feel so long.*

John - *No. But it's an amazing... Has an amazing affect... So, that's gone... All that sort of thing has gone. But there we are. There's nothing you can do about it.*

The participants narrated their engagement with social and physical place as supportive of living with dementia through familiarity, yet this could also enhance a sense of embarrassment and estrangement. Although familiar, a physical place could also come to feel unfamiliar, either because it was not recognized or because over time the landscape developed and altered.

Engaging Services and Supports

Also new to the once familiar physical and social landscape of participants' lives was finding out about and working with supports for those with dementia. Discussion about services and support was wide ranging and included experiences with GPs, older adult psychiatric services, home visits from a Psychiatric Consultant or team member, formal carers, visits to day centres and visits to an independent organisation's activity centre. Many of the participants did not relate to formal services and suggested that invitations to day centres were not welcome. Some of the issues discussed in the interviews in relation to services and support concerned awareness, access, availability, affordability and suitability. There were particular difficulties of tailoring a service response to individual need and accommodating change (with fluctuating and complex needs), both for people with dementia and significant people in their lives. In the following quote, James and his wife Mary talk about the interval between routine appointments.

James - I mean, things may be happening which I don't notice and... that the doctor would spot. It's just... Six month [between routine appointments], I think, is far too long.

[Interviewer] Yes. That can be a good suggestion then. Don't leave people so long between appointments.

Mary - Absolutely, yes. Yes.... For a carer, that's a cold help, cold... [i.e. of little help]

The stakeholders interviewed reflected on some of the specific challenges of delivering services in rural and semi-urban areas. For example, a District Nurse attached to a rural practice, suggested

there can also be a sense of needing to appear independent and not 'bother' others within rural communities:

District Nurse, Rural Practice - *I think it's more so in these communities – farming communities - that kind of individual who wants to be independent. They don't want to ask for help. Different areas, I've worked in different [city] areas and they know what they deserve and they will shout for it, where here is completely different. They'll sit back and [I'll] say, "Well, why didn't you ring?" "I didn't want to bother you, you know."*

A commissioner of local services, including those for people living with dementia, reflected on how wider public attitudes to what can be paid for out of the public purse, may also hinder providing activities that a person can relate to:

Local Commissioner of Services - *We've had the same with what's kind of been called social prescribing, which is those low level interventions to try and prevent people having to go onto medication for, kind of, common mental health problems. And, again, lots of difficulty with "So you're paying people to go painting? And you're paying people to go and read? And you're paying people to go and do this?" But actually it's what goes round to... It's the social inclusion elements – it's getting back into... kind of some kind of routine that will help people manage that. They don't then say, "Oh, we didn't have to pay for medication and... It's immeasurable – the quality of life increases." So I just think it's a challenge, but it's not a challenge that we shouldn't take on.*

Three tensions were evident across all of the data, which reveal both wanting and not wanting information; wanting and not wanting to share the news with family and friends; wanting and not wanting to get in touch with dementia related organisations. Jane's response to the interviewer in the following quote typifies this kind of tension:

[Interviewer] *Is there anywhere else that you might find information from if you wanted it?*

Jane - *I suppose there must be something, somewhere. But I'm not quite sure that I'm ready for it yet.*

In summary, the findings of this study demonstrated a complex pattern of tensions between familiarity and unfamiliarity of social and physical place. These tensions resulted from the interactions between the person with dementia, their close family, wider community members and the physical environment – and led to changes in peoples’ sense of belonging and estrangement. The findings illustrate some of the ways in which citizenship, risk and resilience is understood within individual (personal) and structural (political) contexts.

Discussion

Citizenship and Resilience

Focusing on a group of people living with dementia within rural and semi-urban communities, the study reported here explored the ways in which people narrated their everyday lives. Being able to continue with established roles and activities was central, with many of the participants talking about how changes to the roles and activities compromised their sense of identity and belonging within their communities – their sense of membership as citizens. Von Kutzleben *et al.* (2012), in a systematic review, identified ‘maintaining normality’ as a core need for people living with dementia (either the individual with the diagnosis or a family carer). However, participants in this study discussed how difficult this can be given that a diagnosis of dementia can incur negative and stigmatising public reactions.

Participant’s narratives were played out in physical and social spaces. They had lived in their current communities for at least six years and often all of their lives. Such familiarity was often experienced as very supportive (with people feeling others ‘look out’ for them, for example). However, there is a counter-narrative, and this very familiarity could also prove to be a social barrier – for example, one participant, who had lived and worked all his life within 20 miles of his present home, felt ‘embarrassed’ to be seen ‘out and about’ and that he was no longer the ‘person’ that friends, neighbours and ‘local people’ had come to know.

The experiences expressed by the participants in this study are associated with change and continuity across the life course and specifically in relation to people and place. Beard and Fox (2008) contend that having a diagnosis of dementia can lead to ‘social disenfranchisement’, in which the person with dementia is viewed as having a dramatic rupture in their biography, with habitual ways of living being compromised. What is accepted by others as ‘normal social functioning’, such as the ability to contribute to the local community, may be seen as ‘impaired’. What we see in this present study is that this social disenfranchisement can impact negatively on the person living with dementia, with agency or personhood being diminished and consequently rights, social inclusion and citizenship becoming problematic.

A socio-political understanding of how wider institutional and social organisations position people living with dementia (Adams & Bartlett, 2003; Kitwood, 1997) challenges narrow ‘disease’ focused dementia trajectories. Notions of individual deficits of dependency, incapacity and lack of personhood are shifted from the person to consider environmental, social, cultural, political and ideological ‘deficits’. O’Connor *et al.* (2007) suggest that the bio-medical focus on neurodegenerative changes as leading to irrevocable decline, diminishes recognition that human behaviour is not just a one dimensional neuro-pathological journey but that it is also criss-crossed with personal histories, social networks and socially contextualised perceptions of self by others – these being very evident in the findings of this study as people spoke of living with dementia within well-established yet changing social and physical environments.

Whilst personhood opens up opportunities for self expression and growth (Woods, 2001) and demands that others listen to the person living with dementia (e.g. DeBaggio, 2003; Page & Keady, 2010), Bartlett and O’Connor (2007) assert that citizenship adds to personhood by requiring that what is heard is acted upon. Moreover Baldwin (2008) argues that narrative citizenship may challenge traditional, exclusionary notions of citizenship based on narrow notions of personal rights and responsibilities. In challenging this, Bartlett and O’Connor (2010) expand citizenship to include ‘social practice’. Taking this concept further we would argue that citizenship in practice for people with dementia is co-constructed through the everyday practices that take place between them and their social

and physical environments and manifest in the narratives (or stories) that they tell of their lives as they negotiate daily risks and opportunities. There is an inherently political aspect to citizenship that concerns the positioning of people living with dementia as active and activist in the relationship of their lives with their communities and in seeking to uphold their human rights. In this study, however, the dynamics that led to people feeling, at times, excluded and estranged threatened to undermine the active and activist aspects of citizenship.

People and Place

Echoing Baldwin's (2008) narrative citizenship and the notion that we know of ourselves and others from within inter-related social and physical spaces and places, our findings illustrate the complexity of everyday relationships and attachments to, with and between people and place. For some participants, familiarity with people and places can help in coping with changes and transitions. For others, such familiarity is too revealing of perceived negative changes, as with Jim who avoided visiting local places with friends as 'others' put the spotlight on how he's changed .

Our findings add to a small body of work with people living with dementia that points to local perspective and lifelong knowledge, particularly in rural or small communities, as pivotal to being able to affirm a positive sense of self and identity (e.g. Bailey *et al.*, 2013; Blackstock *et al.*, 2006; Gilmour, Gibson & Campbell, 2003; Hansen *et al.*, 2005; National Institute of Clinical Excellence Guidance, 2006; Szymczynska *et al.*, 2011). This benefit is conferred as a result of other people having knowledge of the individual's past roles and positioning in the community, and through a collective will to support the continuation of some aspects of these roles. In social geography, it has long been recognised that a personal relationship to and understanding of place of dwelling, may have a significant impact on sense of identity and self sufficiency (see for example, Hubbard, Kitchin & Valentine, 2004; Kearns *et al.*, 2000; Wylie 2009). For example, living with dementia in rural communities was studied by Blackstock *et al.* (2006), illustrating the importance of place and person interactions in maintaining community connections and affirming sense of self. In particular, good social networks, a physical relationship with place and a sense of self-sufficiency were nurtured. However, Innes, Archibald, and Murphy (2004), and Parr, Philo and Burns (2004)

caution against romanticising rural living, and indeed the study reported here highlights some disadvantages to social and physical familiarity with a locality, such as the perceived loss of standing or status in the community.

Gilmour, Gibson and Campbell's (2003) qualitative study focused on 10 people with dementia who lived alone in their own homes within dispersed, rural communities in Northern Ireland. Locality was found to be important to managing risk and that the local community knew of and cared about the person living alone with dementia: "Suppose he went out, as he can go out, and some neighbours saw him they would take him back. It's a close-knit thing" (Gilmour *et al.*, 2003, p. 413). A study of 58 people over the age of 65 years and based in Australia, UK, Germany, and South Africa (Moyle *et al.*, 2010) found that maintaining community connections, particularly across the generations, was critical to engendering positive mental health for older people.

Service provision can be challenging too in rural areas because of distances and lack of transport networks, lack of choice of services because of the sparse population and difficulties with staff retention, with Blackstock *et al.* (2006) highlighting "the way in which service provision is configured by the particular economic, social and political geographies of each location" (p. 163). Within our study stakeholder interviews also touched on how wider public and political attitudes may impact on what is considered an appropriate health and social care intervention. For example the commissioner who described being confronted by the comment '*So you're paying people to go painting!*' is challenged with the need to explain that services need to respond to the whole individual not just their disease. Such social prescribing is about responding to what service users' need for continuity and connection to wider society. Living well with dementia is not just about balancing personal risk and resilience, it's also about ensuring that there is a political and social will to maintain inclusive citizenship. This may require its own 'risk taking' and reimagining of services and supports.

Conclusion

The participants in this study highlighted the significance of place connections to their perceptions of who they are, whom others are and the shifting dynamics between social and

physical interactions. Their stories and narratives recount everyday living with dementia, or having a significant role in the life of a person with dementia. For some, life long or long-lived residency within a local community gave them comfortable connections to people and places. They talked of being 'known', of being accepted and of feeling part of the community – they were inside the community. For others, being 'known' created tensions, feelings of embarrassment at being different and also a sense that their 'standing' in their community may be compromised by having a diagnosis of dementia – in these instances, people felt estranged from the social and physical community, or on the outside. Narrative citizenship allows us to explore how people with dementia position themselves in relation to others and in so doing, negotiate their own and other's understandings of dementia. It also allows for people to tell stories about themselves in relation to their sense of belonging in a social and physical place, which augment the personal and political approaches to citizenship and thus offers an approach that enhances individualised yet collective understandings of living with dementia.

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Table One –Interview Schedule

Interview	Indicative Questions
Overall Framework	Each of the four interviews was shaped by a theoretical understanding of aspects of behavior that are known to impact on well-being: daily activities and routines, social networks, community/civic involvement, personal growth (Moyle et al 2010). Prior to the interview, the participant was invited to complete a seven day diary that focused on the interview topic. The interviewer then followed up diary entries, for example, exploring particular interests, activities and contacts. Meaning attributed to these everyday activities was explored to elicit participant’s sense of change/continuity; theirs and others notions of risky behaviour, how they coped/adapted to change, how they perceived their living with dementia.
1. Daily Activities and Routines	Interviewer follows up diary entries that ask about what the participant has done each day, with whom and where the activity took place, e.g.: So you like walking, can you say why? Has it changed in any way? Can you say why? What would you do instead of walking? What doesn’t help you to carry on walking? What might help to carry on walking?
2. Contacts and connections with family, friends, neighbours, professionals and others	Interviewer follows up diary entries that ask about what the participants’ social contacts e.g. Your brother calls in everyday? Is that important to you? Can you say why? If he goes away do you go to the snooker club with someone else? Are there other people whom you meet at the snooker club? What do you like about meeting these people? What makes it difficult?
3. Involvement in civic and community life	Interviewer follows up diary entries that ask about what the participants’ involvement e.g. So staying involved for you is difficult because you no longer drive? I know from your diary that going to the library is important because you like to get help with the computer? What’s good about this help? What’s challenging? [Husband, daughter, friends] drive you to the library, does this work for you?
4. Personal Growth and lifelong interests	Interviewer follows up diary entries that ask about what the participants’ lifelong interests/ personal growth e.g. You say gardening has always been pleasurable for you and still feels ‘safe’? Can you say more about this? You also say that you don’t plan the garden like you did, that [husband] helps but you are still in charge, is this important to you? Can you say why?