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Developing supportive local communities: Perspectives from people with dementia and caregivers participating in the IDEAL programme

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ABSTRACT

Communities play an important role in supporting people living with dementia. The aim of this study was to explore what could be changed in the local community to enable those with dementia to live well. People with dementia and carers taking part in the IDEAL programme responded to open-ended questions. Responses from 1,172 people with dementia and 702 caregivers were analyzed using thematic analysis. Four themes were identified: raising awareness, improving access to support services, providing social events and activities, and supporting people to engage in the community. These highlight the role of individuals, resources and the environment in supporting those with dementia. Longer-term investment in services is needed to underpin dementia-inclusive communities.

Introduction

It has been forecast that the global population of people aged 60 and over will increase from nine hundred million in 2015 to two billion in 2050 (World Health Organization [WHO], 2018). Whilst an increasing aging population should be perceived as a positive reflection of improvements to health and long-term care, with age comes the increased risk of age-related conditions such as dementia. Estimates indicate that worldwide there were 46.8 million people living with dementia in 2015 (Alzheimer's Disease International [ADI], 2015). It is estimated that 66% people with dementia from high income countries, and 94% from middle-low income countries, reside in the community (ADI, 2010). Given these numbers, it is imperative that people with dementia can reside in a community that is supportive and enables them to

continue living well for as long as possible. Whilst creating 'dementia-friendly,' 'dementia-inclusive,' and 'dementia-capable' communities is an increasing focus in policy (e.g., Alzheimer Europe, 2018; Department of Health, 2012; U.S. Department of Health and Human Services, 2019); it is vital to understand, from the perspective of those living with dementia or caring for someone with dementia, what is needed to ensure that people with dementia can remain part of these communities. This paper will explore the views of people with dementia and informal caregivers on how communities can better enable people with dementia to live well.

Dementia is a progressive degenerative condition which impacts on global cognitive functions, such as memory, language, and problem-solving. This will gradually affect a person's ability to carry out activities of daily living, such as cooking or washing (Alzheimer's Association, 2018). People with dementia face many challenges in maintaining their involvement in the community; for example, their memory difficulties can make it difficult for them to go shopping or use public transport (Alzheimer's Society, 2013). People with dementia may have restricted opportunities for social participation, leading to a loss of social connection in their community (Biggs et al., 2019). Dementia also has an impact on a person's confidence; underlying worries and fears may prevent people from engaging in activities (ADI, 2019; Alzheimer's Society, 2014). Worldwide, governmental policies acknowledge the importance of enabling people with dementia to continue residing in the community (ADI, 2016; Alzheimer Europe, 2018), identifying benefits for the individual and the economy, as this reduces the need for costly residential or hospital care (ADI, 2016; Alzheimer's Society, 2013). The development of dementia friendly communities (DFCs) arose from this need to support people to remain in and actively participate in their community.

The concept of creating DFCs is embedded within the age-friendly environments movement (WHO, 2018). These seek to foster healthy and active aging by "fostering the functional ability that enables older people to be and to do what they value" (WHO, 2020, p. 3). Age-friendly communities focus on enabling people to age actively by promoting their inclusion in all areas of community life; recognizing the role of infrastructure, services, and how the person is treated by others (WHO, 2018). Age-friendly communities seek to enable people to reside in their homes for as long as possible, linking to the concept of 'aging in place.' Older people may see living in their own homes as a way to maintain autonomy and independence; and they may value familiarity with their surroundings and preexisting social connections with local communities (Wiles et al., 2012).

Although there are similarities in the conceptualizations of age-friendly and dementia-friendly communities, there are some crucial differences. Some people with dementia are under 65, with a diagnosis of young-onset dementia. Unlike age-related decline, dementia impacts on both cognitive and functional

abilities, so people with dementia require additional support to remain in the community. The stigma associated with dementia can also result in social isolation, as loss of friends and social contacts can follow after a diagnosis (Alzheimer's Society, 2017). In fact, tackling stigma and raising awareness of dementia is one of the key elements of DFCs (Department of Health, 2012; WHO, 2017).

There are differences in the terminology used within countries, with most referring to 'dementia-friendly,' whereas the United States emphasizes 'dementia-capable' communities (Lin & Lewis, 2015). The 'dementia-friendly' approach focuses more on the lived experience of dementia and involving people directly in the community through making modifications to the living environment. The 'dementia-capable' approach considers people with dementia as part of the disability community. This results in a two-phase approach to involving them in the community, first by including them in the disability community and second by promoting the inclusion of people with disability in the community (Lin & Lewis, 2015). Both approaches aim to improve the quality of life of people with dementia and to some extent also of those providing care for them.

Despite differences in terminology, DFCs initiatives have been launched in many countries such as in the United States (Dementia Friendly America, 2018), Japan (ADI, 2020), and the United Kingdom (Alzheimer's Society, 2013). It has been proposed that the DFCs initiative was inspired by the 2004 campaign in Japan to develop a better understanding of dementia and build community networks (ADI, 2016). The implementation of DFCs varies from country to country, but generally encompasses societal and environmental initiatives to improve the environment that people live in and the education of people within these communities (Fleming et al., 2017; Hebert & Scales, 2019). While the environment needs to be accessible and optimize involvement (WHO, 2017), people in these communities need to provide extra support to enable people with dementia to live in and be part of the community (Department of Health, 2012). The characteristics and design of DFCs are unique to the area in which they are established and are developed through a stakeholder panel who establish the priorities for the DFC (BSI, 2015). Both people with dementia and caregivers should be part of this stakeholder panel and have meaningful involvement in the development of DFCs (ADI, 2016; BSI, 2015). DFCs undertake a range of approaches to achieve the identified priorities; for example, training volunteers to promote dementia awareness (Woodward et al., 2019). To be effective, DFCs need to be developed in partnership with local government, organizations, and businesses (ADI, 2016; BSI, 2015).

Despite the principle that people with dementia and caregivers should be involved in the development of DFCs, there are challenges in involving them as stakeholders (Heward et al., 2017) and there is some evidence that their

perspective may under-represented in this process (Buckner et al., 2019; Hebert & Scales, 2019). Swaffer (2014) observed that despite the growth of dementia-friendly initiatives, less attention has been paid to the perspectives of people with dementia on what makes a community dementia-friendly. Research on exploring how communities can better support people with dementia has tended to focus on perceptions of the physical environment in neighborhoods (Mitchell & Burton, 2010), the meaning of DFCs (Crampton & Eley, 2013), and the experience of living in a DFC (Darlington et al., 2021). Wiersma and Denton (2016) explored how dementia-friendly rural communities in northern Ontario (Canada) were; of the 71 people interviewed, however, only 2 were people living with dementia. Smith et al. (2016) explored the re-building of the Christchurch (New Zealand) community in response to the 2011 earthquake, with a focus on how people with dementia could live better. The findings suggest people wanted more support services, better transport, and greater awareness of dementia. However, this was a small sample of 26 people with dementia, of whom 20 lived in the community and 6 were in care homes, and the data reflect the post-quake situation for that small community. Wu et al. (2019) interviewed 16 people with dementia and 20 family caregivers from Taipei in Taiwan about whether the community was dementia-friendly. Participants identified the need for dementia-friendly transportation, dementia-friendly shops, and opportunities for people to be involved in the community. Both Smith et al. (2016) and Wu et al. (2019) studies were on a small scale, focusing on a specific community or region.

To our knowledge there appears to be little empirical evidence, from the perspective of people with dementia and caregivers, about changes in the community that would help people with dementia to live well. Yet there is growing evidence-base on the factors that influence the capability of people with dementia to live well. These include feelings of isolation, levels of social engagement and connectedness with others and the environment, independence in daily activities and ability to manage everyday life (Clare et al., 2019; Martyr et al., 2018; O'Rourke et al., 2015). These findings imply that it is more than just the physical environment and the education of people within the community that enables people to live well. Thus, it is important to explore the views of people with dementia themselves on how they could be better supported. Equally, caregivers of people with dementia can provide a valuable perspective on what would make a difference within the community. The aim of this study is to explore, from the perspective of people with dementia and caregivers, what could be changed in the local community to enable those with dementia to live well.

Methods

Design

This study utilized data from v4.5 of the time-point 1 dataset of the IDEAL cohort study (Clare et al., 2014; Silarova et al., 2018) collected from 29 National Health Service sites within Great Britain between June 2014 and August 2016. IDEAL was approved by the Wales Research Ethics Committee 5 (reference 13/WA/0405), the Scotland A Research Ethics Committee (reference 14/SS/0010) and the Ethics Committee of the School of Psychology, Bangor University (reference 2014-11684). The study is registered with UKCRN, registration number 16593.

Participants

Participants were people with dementia and their informal caregivers. People with dementia were eligible to take part in time-point 1 of IDEAL if they were residing in the community, had a diagnosis of dementia (any sub-type), and a Mini-Mental State Examination (Folstein et al., 1975) of 15 or above, indicating that they were in the mild to moderate stages of dementia. The exclusion criteria were a co-morbid terminal illness, inability to provide informed consent and if there were any risks to researchers conducting home visits. Caregivers were eligible to take part if the person with dementia they cared for consented to take part in the study. The caregivers had to be the primary caregiver and provide practical or emotional unpaid support to the person with dementia.

Among 3105 people with dementia who were approached to take part in the study, 378 were ineligible, 1106 declined and 81 withdrew subsequently. The response rate was 56% among eligible people with dementia. There were 1607 caregivers who were approached to take in the study. Of these caregivers 240 declined, and of the 1367 initially consented, 89 withdrew or were no longer eligible to continue during T1 assessment. The response rate was 80% among caregivers approached.

Data collection

Researchers from clinical research networks were responsible for participant recruitment and assessment. Participants were identified and recruited through memory services and other specialist clinics within the UK National Health Service (NHS), and via the online Join Dementia Research portal (an UK based online service that enables volunteers, including people with dementia, to register their interest in taking part in research). Potential participants were contacted about the study and those who expressed an interest were visited by a researcher who completed eligibility checks and

obtained informed consent. The person with dementia was administered the assessments by the researcher, whilst the caregivers self-completed their assessments but could seek help from the researcher if necessary. Details of the assessments included in IDEAL are reported in the protocol (Clare et al., 2014). This study utilized data from one open-ended question. People with dementia were asked "What do you think could be changed in the local community to enable people like yourself to live well?," while caregivers were asked "What do you think could be changed in the local community to enable people with dementia to live well with dementia?"

Data analysis

We used thematic analysis to identify and explore patterns within the data. We took an inductive approach whereby the coding of the responses is data driven and not influenced by a preexisting coding frame or the researcher's analytic pre-conceptions (Braun & Clarke, 2006). Responses of people with dementia and caregivers were analyzed separately. Data analysis was conducted in a recursive process, going back and forth between the various stages of analysis. The first stage involved becoming familiar with the data before each participant's response was analyzed and coded by a researcher (CQ). Once this process had been completed, similar points were clustered together to identify themes. Related themes, referred to as sub-themes, were then grouped together under theme headings. The content of these themes was checked to ensure that there were similarities within the extracts. This process involved discussion with two other researchers (NH and CH) who acted as 'critical friends' (Smith & McGannon, 2018) and commented on the structure of the themes, and any differences were resolved by consensus to generate a final list of the themes.

Several steps were taken to enhance the credibility of the analysis. The datasets for people with dementia and caregivers were analyzed separately; this ensured that the identification of themes from one group of participants did not influence the identification of themes from the other group of participants, in line with the inductive approach selected for data analysis. Although ultimately there are commonalities in the themes identified from the accounts of people with dementia and caregivers, the analysis highlights both similarities and differences. The descriptions of the themes were illustrated with extracts from the accounts of a range of participants (provided in Table 3) to ensure the findings are grounded in the data (Whittemore et al., 2001). Due to the interpretative nature of data analysis, it is important acknowledge the researchers' preconceptions and knowledge of the topic that could influence their approach. None of the researchers who analyzed the data were involved in the data collection process and so the analysis is purely based on participants' responses. Three researchers (CQ, NH, CH) were involved in the analysis process, which means that the

analysis does not reflect one person's viewpoint. Although we were unable to return to the original participants to discuss the analysis, the findings were presented to the IDEAL involvement group (the ALWAYs group) which consists of caregivers and people with dementia. ALWAYs group members felt that the identified themes fitted with their experience and resonated with described the challenges they faced within the community.

Results

Out of the 1540 people with dementia taking part, 1172 responded to the question "What do you think could be changed in the local community to enable people like yourself to live well?." Of these, 827 detailed possible ways of enabling people to live well with dementia in the community, 322 were unsure about what changes could be made, and 23 said they did not know what was available in their local community. Out of the 1278 caregivers taking part, 702 responded to the question "What do you think could be changed in the local community to enable people with dementia to live well with dementia?" Of these, 595 suggested changes in the community to enable people to live well with dementia, 85 were unsure about what changes could be made, and 22 said they did not know what was available in their local community. It is important to note that within their responses, rather than suggesting changes to their community, some participants gave examples of positive aspects of their communities that helped them to live well, such as describing support groups they attended and found helpful.

Details of participants are recorded in Table 1. Just under half of the people with dementia were female (44.6%) and 56% were diagnosed with Alzheimer's disease. Over two-thirds of the caregivers were female (73.6%), the majority were spouses/partners (77.5%), and just over a third (38%) were providing care for over 10 hours per day.

Four themes were identified from the data (See Table 2). First, greater societal awareness and understanding can be raised through more education and training about dementia. Second, better support is needed through improvements in support services. Third, people need access to activities and social contact. Last, to actively engage in the community, people with dementia need access to an environment that is adapted to meet their needs. There were some differences in what was considered important by people with dementia and caregivers. Underpinning all these themes is the importance of people, resources, and the environment. Table 3 contains example quotes for each theme.

Greater awareness and improved understanding

Both groups of participants contended that there needed to be more awareness and understanding of dementia within the community. This was a particularly salient issue for caregivers; people with dementia did talk about this issue but

Table 1. Characteristics of the caregivers and people with dementia.

Demographics	N
People with dementia	N = 1172
Gender: Female	523 (44.6%)
Age: <65	101 (8.6)
65–69	144 (12.3)
70–74	201 (17.2)
75–79	283 (24.1)
80+	443 (37.8)
Education*: No qualification	326 (28.4)
GCSE/equivalent	208 (18.1)
A level/equivalent	395 (34.4)
College	220 (19.1)
MMSE score *M* (*SD*)**	*M* 23.38 (3.53)
Diagnosis: Alzheimer's disease	656 (56)
Mixed dementia	243 (20.7)
Vascular dementia	122 (10.4)
Lewy body dementia	42 (3.6)
Frontotemporal dementia	41 (3.5)
Parkinson's disease dementia	37 (3.2)
Unspecified/Other dementia	31 (2.6)
Living situation***: Living alone	227 (19.4)
Living with spouse/partner	880 (75.1)
Living with other person	61 (5.2)
Caregivers	n = 702
Gender (female)	517 (73.6)
Age: <65	233 (33.2)
65–69	126 (17.9)
70–74	146 (20.8)
75–79	113 (16.1)
80+	84 (12)
Kin-relationship: Spouse/partner	544 (77.5)
Other family/friend	158 (22.5)
Education****: No qualification	124 (18.3)
GCSE/equivalent	158 (23.3)
A level/equivalent	193 (28.4)
College	204 (30)
Hours of care*****: <1 hour	117 (17.2)
1–10 hours	243 (35.8)
10+ hours	258 (38)
Other responses	61 (9)

MMSE = Mini-Mental State Examination score, Hours of care = hours of care provided on an average day. *Missing data for 23 participants, **Missing data for 51 participants ***Missing data for 4 participants, ****Missing data for 23 participants, *****Missing data for 23 participants.

to a lesser extent. Society must understand the nature of dementia and the difficulties that people with dementia face, whilst also recognizing that everyone's individual experience will differ. Both caregivers and people with dementia wanted to remove the stigma associated with dementia.

Generally, it was felt that if people were more understanding of dementia then they would treat people with dementia better. People with dementia wanted to be treated as individuals. Some wished to be treated the same as people who did not have dementia, whilst others described the need for adaptation, such as information being provided at a slower pace, to enable

Table 2. Categories identified from the analysis.

Theme	Number of extracts coded in the caregiver data	Number of extracts coded in the person with dementia data
Greater awareness and improved understanding	252 (31.6%)	96 (10.4%)
Support when you need it	306 (38.4%)	231 (25.1%)
Access to social events and activities	111 (13.9%)	156 (16.9%)
Support to actively engage in the community	128 (16.1%)	438 (47.6%)

The counts equate to the number of extracts encoded from the participants' accounts; participants' responses may have been coded under more than one category. The percentages are derived from the total number of extracts coded.

them to remain independent. Participants hoped that increased understanding of dementia would result in people with dementia being treated 'properly' with 'patience and understanding.'

One identified route for improving understanding of dementia was through education and training to raise people's awareness of dementia, and therefore their ability to provide effective support. There was a desire for staff in both local and national public-facing organizations, such as banks, shops and cafes, to receive training to enable them to be more 'dementia-friendly.' Front-line staff needed this training as they were particularly likely to be in contact with people with dementia. This training should cover issues such as the impact of the physical environment; for example, supermarket layouts could be confusing. Service workers also needed to understand that people with dementia may require extra time to complete tasks, such as paying at the till. There was some recognition that things were improving, as participants gave examples of good practice where organizations had been very supportive. However, overall people with dementia expressed a need for more support to enable them to continue living their lives.

Other strategies were proposed for increasing awareness: a national 'dementia awareness' campaign and highlighting issues in television programmes or advertisements. More locally, community awareness could also be raised through adverts in public places such as doctor's surgeries. Some suggested that there needed to be more openness about dementia; for example, more people talking about their 'real life' experiences of dementia. Although, it was recognized that not everyone would be comfortable discussing their diagnosis. If community members were more informed about dementia, they would be able to identify people with dementia and make 'allowances' for them.

Support when you need it

Both people with dementia and caregivers wanted access to appropriate dementia support services, both paid and unpaid, and better access to health care. People needed help to live independently; this could involve support with

Table 3. Sample quotes for each theme.

Theme	Example extracts from participants' responses
Greater awareness and improved understanding	"If there were more understanding people treated you as a person. To be treated properly, like a normal human being" (person with dementia) "There is still a lot of stigma attached to dementia, just more awareness that it is no different to a broken leg or arm, some people feel ashamed as if it is their fault." (caregiver) "Shop staff being aware of people with dementia and being aware of some of the problems they face. People like me get money muddles . . . find PIN numbers hard to remember, so would need . . . to be aware of this" (person with dementia) "Make local community aware of dementia and that there may be people living around them . . . make more allowances for slightly altered behaviour and to support the caregiver" (caregiver) "Alzheimer's is a silent menace and there is no way for people to be aware of it like people with blindness have a white stick. The only way you can let them know is by saying and sometimes people don't want to do this." (person with dementia)
Support when you need it	"Having someone to call for support when in a muddle. Not professional but accessible to everyone" (person with dementia) "People help each other in a local community; however, you will still find people on their own and alone with no one to look out for them. Those are the people one needs to find and support." (caregiver) "We need to be able to meet with people with the same memory problems. To discuss issues that affect us. Discussing this together means we are not being judged or looked at" (person with dementia) "Groups for people with dementia and their caregivers to share problems and to see how some people deal with these" (caregiver) "There's a lot out there but I just need to ask, and there's a barrier I feel to being able to ask" (person with dementia) "I think they should make it easier to ask for help if you think you need it, it's only the Memory service that told us about the services available" (caregiver)
Access to social events and activities	"Somewhere where I could go to find things to do and provide more stimulation" (person with dementia) "The singing group works for my mum. More classes e.g., bingo, dancing, tea parties in the summer" (caregiver) "Someone to come and take you out for a walk or a ride out somewhere to get out of the house, even an hour would be fine" (person with dementia) "Organise trips out with companions for those who need them" (caregiver) "This business of living well, it is a lonely existence unless I/we make an effort to communicate with others" (person with dementia) "More befriending services for those people who have no family or friends to rely on" (caregiver)
Support to actively engage in the community	"I'm lucky in my neighbourhood that everyone looks out for me" (person with dementia) "People in the community where possible, visit them albeit for a short time of letting them know that they are still members of the local community!!" (caregiver) "Having better transport or 'community drivers' to taxi people to where they want to go. I can't get anywhere without my wife" (person with dementia) "Fortunately we have a group [anonymized] who collect and drop off elderly people . . . they are aware that mum has dementia and help her get her things together (caregiver) "I would like to be able to go out into town and if I became disorientated or lost I would like to know that others would be understanding and offer me help" (person with dementia) "Signage to be more dementia friendly, a picture of what it is as well as words" (caregiver)

practical tasks such as shopping or finances. People with dementia also needed to be able to access help if there was a crisis or an emergency, and support should be accessible to all. In terms of the types of dementia-specific support services, there needed to be more facilities, such as accessible drop-in centers or day centers. It was identified that more funding was needed to sustain and increase such 'voluntary' services. In addition, given challenges people faced with transportation there was a need for local services to serve people in the immediate vicinity.

When people could access dementia-specific services, these were valued as a way of "breaking down barriers" and enabling people to "take their mind off" the diagnosis. People with dementia and caregivers appreciated having dementia support or meeting groups where people can share their problems and learn from each other. These groups provided opportunities to meet others with the same 'problems' who would understand them and not 'judge' them.

There needed to be more tailored services for people with dementia. Some felt there needed to be different dementia support groups for people based on the severity of dementia and the person's level of abilities. For some, this was because of the different types of advice and support needed for the different stages; others felt that including people with more advanced dementia may be upsetting for those in the early stages. It was also identified that there needed to be more services for those with early-onset dementia as not all people living with dementia were in their '70 or 80s'. Both caregivers and people with dementia identified that separate support was also needed for caregivers. This could be through a support group specifically for caregivers or volunteers enabling caregivers to have short breaks from caring.

In order to access appropriate support, caregivers and people with dementia needed signposting to the types of support on offer. It was identified that this process needed to be made easier since some did not know about local services and others had to wade through 'paperwork' on what was available. Often the onus was on the person having to 'ask' about what was on offer, when they would prefer people approaching them. There was a clear need for better ways of informing people about these services, such as having posters in public places or local 'enablers' who could put people in touch with local resources and help. More centralized points of information or more information points within the community were also suggested

Access to social events and activities

As well as access to dementia-specific support services, caregivers and people with dementia described the importance of the person with dementia having access to general social events and activities happening in their communities. These activities were not dementia-specific and were open to all such as 'coffee

mornings' or something more structured that provided activities. Activities enabled people to have 'something to do' and could involve cultural activities, quizzes or bingo. These could also encompass stimulating activities and keep them active.

Providing opportunities for the person with dementia to engage in exercise was also seen as important, whether this be football, dancing, or walking. People wanted more opportunities for exercise; facilitated through having access to facilities such as such as swimming pools, exercise parks, gyms, or indoor bowling. Equally there needed to be opportunities for people with dementia to leave their community and be able to go out on day trips or coach tours or have places to go such as the opera or theater. This might involve people with dementia being paired with a 'companion.' Related to this was a need to improve opportunities for social connections. In particular, people with dementia identified that people could feel isolated, particularly those who lack transport to get out and about. Having human contact was incredibly important, otherwise it was a 'lonely existence.'

Suggestions for improving opportunities for social contact included the provision of facilities such as local community centers. Buddy or befriending schemes could be particularly valuable for people living alone or those without any family or friends to rely upon. These schemes would allow for someone to accompany the person with dementia, for example, on a walk. There was acknowledgment that one of the main barriers to accessing such services was funding, some gave examples of services that no longer ran because of lack of funding. It was difficult when an enjoyed service was stopped for these reasons.

Support to actively engage in the community

This topic was clearly more salient to people with dementia than caregivers. Being able to live well involved feeling part of a community. Community engagement involved both interacting with others but also people looking after one another. The local community had a role in enabling people to continue living with dementia in their own homes. For instance, community members, such as neighbors, could provide both support for people with dementia and keep an 'eye' on them. Equally, members of the community could visit them in their own homes.

The outdoor environment was perceived as being important in enabling people to remain active and continue residing in the community. This required appropriate accommodation with good access to local amenities, such as shops and libraries. Equally, people with dementia wanted to maintain access to the wider community, to 'get out and about,' and suggested ways in which the outdoor environment could be changed to improve access. People with dementia wanted more benches so they would have somewhere to rest. Well-maintained footpaths were also vital in allowing people with dementia to

walk or use wheelchairs without the risk of falling. People also needed access to transport to get out and about. Being able to get out meant that people with dementia felt less isolated and could attend support groups or go to medical appointments. Those who still drove a car wanted better parking options, closer to amenities. Those unable to drive saw buses as a vital means of transport and wanted more local bus stops and more frequent services. Some people relied on community transport services to 'taxi' them to places.

In addition to improved transport, people with dementia needed to be able to navigate effectively within their community: clearer signage was needed. This would help people to be able to navigate shops, but also find their way around their neighborhood. The need for better signage was linked to concerns about people with dementia getting lost. It was felt that safe places could be set up for them to go to, or people in the community could be identified to look after them if they got lost. Caregivers suggested people with dementia should have some marker to let the wider general public know that they have dementia or an identity bracelet in case they got lost. For people with dementia, what was more important was having people in the community who would be willing to help them if they became disoriented or lost.

Discussion

This study identifies four main areas for enabling people with dementia to live well in the community. The identified themes focus on raising awareness, improving access to support services, linking to social events and activities, and supporting people to engage in the community. The identified themes are interlinked, as improvements in one domain will likely lead to subsequent improvements in the others. Underlying these themes is the importance of three factors. Making communities more inclusive for people with dementia is the role of individuals, resources (public, corporate and societal), and the environment (physical and social) that the person resides in. All these three elements are essential to enable people with dementia to continue living well in the community.

This study highlighted the role of individual members of the community in supporting people with dementia by having an understanding of dementia. Raising awareness and understanding of dementia in those within the community was a particularly salient issue for caregivers. It is possible this was because caregivers felt more socially isolated because of their caregiving role. If others were more aware of the challenges they faced, they would feel more supported. Equally, it is possible this was because caregivers were more aware of the stigma associated with dementia and felt this is an important area to address within the community. Caregivers can experience 'stigma by association' and may socially isolate themselves to avoid exposing themselves to the reactions of others (ADI, 2012). Challenging stigma and increasing awareness

of dementia is a core principle of dementia-friendly initiatives (Alzheimer's Society, 2013). Indeed, when defining DFCs, people with dementia have focused on issues of acceptance, understanding, respect, and a lack of stigma (Imogen Blood & Associates & Innovations in Dementia, 2017). Raising awareness of dementia in organizations and services is also a component in many dementia-friendly initiatives (Alzheimer's Society, 2013; Dementia Friendly America, 2018). An informed workforce would help people with dementia to feel more confident in using these services, enabling them to maintain their independence and daily life.

The importance of individuals in the wider community was also related to the resources within the community. Both caregivers and people with dementia described the importance of resources to enable opportunities for social contact and to do activities such as exercise. People with dementia can find themselves having to give up exercise activities (Alzheimer's Society, 2013). Social contact is important as people with dementia can be more at risk of experiencing loneliness if they are socially isolated or live alone (Victor et al., 2020). Certainly, both people with dementia and caregivers in this study expressed concerns about those people living alone, identifying they were at risk of being isolated and therefore in need of support. This is in line with findings that people with dementia living alone have higher unmet needs and are more isolated (Clare et al., 2020; Miranda-Castillo et al., 2010). Wiersma and Denton (2016) identified that people with dementia living in a community who were isolated and not well-connected before the dementia may not be as supported by the community as those with stronger connections.

Participants wanted access to dementia-specific support services; they particularly valued peer-support services run by voluntary organizations, which enabled them to share their experiences. Support groups can be beneficial for people with dementia, with evidence indicating that people enjoy meeting together and often form close bonds (Toms et al., 2015). Caregivers may value having separate support so that they can share their concerns with others with the person they care for being present. Tailored support services can also be beneficial; for instance, services that provide advice and information specific to young-onset dementia have been positively received (Stamou et al., 2021). Participants reported difficulty finding out about support services available in their communities. More assistance is needed to help people navigate care pathways to enable access to the appropriate services.

The resources available in the local area related to the role of the physical environment in enabling people to feel part of the wider community. Feeling a part of the community was a particularly salient issue for people with dementia. It is possible that this is because they were more aware of the disabling world around them and the challenges of trying to remain part of the community. It is acknowledged that people with dementia need to be appropriately supported and empowered to remain part of the community

(WHO, 2017). Definitions of dementia-friendly societies acknowledge the importance of accessible community environments (WHO, 2017). Yet people with dementia are less likely to go out, with a survey finding 35% of people with dementia only go out once a week, and 10% once a month or less (Alzheimer's Society, 2013). The findings of this study highlighted small changes, such as improving signage, and more large-scale changes, such as improving transport, that could help people with dementia to remain involved within the community.

Although this study focused on how the local community could better support people to live well with dementia, the findings have some potential implications for DFCs. In terms of the development of DFCs our findings are broadly in line with the key areas typically targeted by DFCs – the physical and social environment (ADI, 2016). Key areas identified by our participants relating to raising awareness, improving support, the provision of accessible activities and improvements to the environment are all core components of DFCs (ADI, 2016; BSI, 2015). Given the slight differences in the priorities identified by people with dementia and caregivers, this highlights the importance of including both people with dementia and caregivers as stakeholders in the design and development of DFCs, particularly as Heward et al. (2017) found that caregivers may be more likely to be involved as stakeholders than people with dementia. The findings also highlight the importance of DFCs being designed to meet the needs of both people with dementia and caregivers.

Implications for policy

There is an increasing policy focus on enabling people with dementia and those that care for them to have a good quality of life. The World Health Organization call for 75% of countries to have developed or updated national policies or strategies for dementia by 2025 (WHO, 2017). Whilst the policy literature predominantly focuses on diagnosis and post-diagnostic support, there is some acknowledgment of DFCs' role in raising awareness and reducing stigma and social isolation (Alzheimer Europe, 2018). As the findings of this study demonstrate, there are other factors to consider when supporting people with dementia living in the community. This study provides an evidence-base from the perspective of people with dementia and caregivers which can underpin the development of better support for people with dementia and caregivers within the community. First, activities to raise greater awareness of dementia need to continue. These can be provided at a local level through dementia-friendly initiatives within the community but equally they should be underpinned by the wider public awareness campaigns that form part of dementia strategies (Alzheimer Europe, 2018). Second, approaches to support people living with dementia also need to encompass support for caregivers. There is an increasing recognition of the importance of 'dyadic' relationship between

caregivers and people with dementia, and the impact that the wellbeing of one members of the dyad may have on the other (e.g., Quinn et al., 2019). Third, whilst participants acknowledged some improvements needed in health and long-term care, it is clear they particularly valued the services provided by voluntary organizations. Whilst such services can complement those provided by statutory organizations, they cannot entirely replace them. A lack of long-term funding challenges the sustainability of such voluntary organizations. Last, participants identified many changes that needed to take place within the physical environment in the community. This requires both local community initiatives but also wider support from local government; for example, continuing to provide public transport services. Although this study included the perspective of both people with dementia living alone and living with others; it is important to recognize that people with dementia living alone may require additional support from the community, particularly those who are not well-embedded within their communities. Thus, local community and service providers need to be responsive to the particular needs of those living alone.

In terms of policies relating to DFCs, the findings suggest that for these initiatives to be successful they require a wide range of stakeholders and partners involved to implement changes. Some of the areas identified from this study clearly require complex changes; for example, improvements to health care or improving signage in the community. Most DFC initiatives place the onus on the local community to make changes, yet the findings indicate a need for changes in infrastructure, such as the longer-term funding of services. For example, community initiatives were clearly valued by the participants, yet sustaining such initiatives can be challenging as there can be changes within politics, society, and the economy (Fitzgerald & Caro, 2014). The integration of DFCs into policy may be one means for driving the development of DFCs forward; for example, in England the creation of DFCs is an explicit policy goal (Department of Health, 2016). The findings highlight the need to take people with dementia and their caregivers' perspectives in developing dementia strategies. Policies relating to aging tend to be very fragmented; many health systems lack integration with long-term care services. It would be more effective to take a holistic approach that meets the needs of individuals and their families (Pin & Spini, 2016). For dementia policies, this holistic approach needs to encompass the role of individuals, resources, and the environment in supporting people with dementia in the community.

Limitations

In considering the findings of the study it is necessary to reflect on the strengths and limitations. This study involved a large cohort of caregivers and people with mild-to-moderate dementia from different regions within

Great Britain. Thus, the analyses incorporate perceptions of different communities. This study does not include the viewpoints of those with more advanced dementia; however, these people are more likely to reside in long-term care. The data collected were part of a wider survey study and as such we were unable to ask participants follow-up questions on their responses. Equally, this was an optional open-ended question toward the end of the survey and it is likely this resulted in some participants opting not to answer the question. Whilst the format limited the depth of responses, the large number of respondents involved does give breadth. Whilst three researchers were involved in the analysis, two of these people acted as 'critical friends' and thus we did not measure inter-rater or inter-coder agreement. Although inter-rater reliability is a commonly used measure of reliability there are limitations of this approach; for example, each researcher's own bias and knowledge can influence the coding, making it harder to agree on a coding framework. The 'critical friends' approach focuses more on encouraging reflectivity and discussion rather than achieving consensus in coding (Smith & McGannon, 2018).

Conclusion

In conclusion, in a large cohort, this study has explored the perspectives of people with dementia and caregivers on changes that could be made to the community to enable people with dementia to live well. The findings identify four core areas of awareness, support services, social events and activities, and supporting people to engage in the community. These are shaped by individuals' attitudes, availability of resources, and the environment. Whilst some of these changes can be implemented at a community level, others require support through policy and infrastructure underpinned by longer-term investment in services.

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