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‘Dementia-friendly communities’ and being dementia friendly in healthcare settings

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Abstract

Purpose of review—This review discusses the concept of ‘dementia-friendly communities’ and summarizes the latest research and practice around such communities. This review also highlights important topic areas to be considered to promote dementia friendliness in healthcare settings.

Recent findings—Definitions of ‘dementia-friendly communities’ reflect the contemporary thinking of living with dementia (e.g., dementia as a disability, equal human rights, a sense of meaning). Existing research has covered a wide range of topic areas relevant to ‘dementia-friendly communities’. However, these studies remain qualitative and exploratory by nature and do not evaluate how dementia-friendly communities impact health and quality of life of people living with dementia and their caregivers. In healthcare settings, being dementia friendly can mean the inclusion of people with dementia in treatment discussion and decision-making, as well as the provision of first, adequate and appropriate service to people with dementia at an equivalent standard of any patient, second, person-centered care, and third, a physical environment following dementia-friendly design guidelines.

Summary—Research incorporating more robust study designs to evaluate dementia-friendly communities is needed. Being dementia-friendly in healthcare settings requires improvement in multiple areas – some may be achieved by environmental modifications while others may be improved by staff education.

Keywords

concept exploration; dementia-friendly communities; dementia-friendly healthcare

INTRODUCTION

More than 47 million people worldwide are living with dementia [1]. With a 7.7 million projected annual increase, the number of people living with dementia (PWD) is expected to exceed 135 million by 2050 [1]. To ensure a better life for this rising number of PWD and their families, consumers, policy makers, and researchers around the world have begun exploring and embracing the concept of ‘dementia-friendly communities’ [2].

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Conflicts of interest

There are no conflicts of interest.

Despite their growing popularity, there is no set meaning for ‘dementia-friendly communities’. The interpretation of the term is often context-dependent. For example, in a 2012 report published by the World Health Organization (WHO) and the Alzheimer’s Disease International (ADI), ‘dementia-friendly communities’ was conceptualized as an ‘approach’ to normalizing dementia in society [3]. In contrast, when the term ‘dementia-friendly communities’ was interpreted in the United Kingdom (UK), it contained at least three other meanings:

1. A policy initiative, which was one of the three areas of action outlined in the *Prime Minister’s Challenge on Dementia*, that encourages cities, towns, and villages to sign up to become more dementia-friendly [4,5].
2. An Alzheimer’s Society programme ‘Dementia-Friendly Communities,’ that was established under the aforementioned policy initiative to facilitate the creation and recognition of dementia-friendly communities across the country [6].
3. The cities, towns, and villages that have been publicly recognized for their work towards becoming dementia-friendly through Alzheimer’s Society’s ‘Dementia-Friendly Communities’ recognition programme [7].

In this review, ‘dementia-friendly communities’ refers to ‘any communities working towards becoming dementia friendly’, unless otherwise specified.

COMMUNITIES WORKING TOWARDS BECOMING DEMENTIA FRIENDLY

Even within the context of ‘communities working towards becoming dementia friendly,’ the definitions of ‘dementia-friendly’ and ‘community’ remain diverse. As demonstrated in the three examples given in Table 1, the concept of ‘dementia-friendly’ may target PWD [8,10], or both PWD and their caregivers [11■]. Even though most would agree that a critical way to support PWD is to support their caregivers, many insist that PWD should remain central when defining ‘dementia-friendly’. To add to another level of complexity, the concept of ‘community’ may represent a place, the social and physical environments, an organization, a group of individuals, a society, a culture, or virtual communities [9■,10,11■]. What ‘community’ means to one may be completely different from another. Additionally, as the interpretation of ‘dementia-friendly’ can be shaped by the political, social, cultural, historical, economical, moral, and other factors that surround a community, so are the defining attributes of ‘dementia friendly’. For example, in Definition 1, the defining attributes of ‘dementia friendly’ are empowerment, aspiration, self-confidence, contribution, participation, and meaningful activities [8]. These attributes may imply that the purposes of becoming dementia friendly are to acknowledge the ‘personhood’ of PWD [12], and to sustain their sense of meaning in life. In Definition 2, the essential attributes of ‘dementia-friendly’ include way-finding ability, a sense of safety, accessibility to local facilities, social acceptance, and understanding of dementia [10]. The emphasis on community accessibility and social acceptance may represent the view of dementia as a type of disability. Lastly, the attributes of ‘dementia-friendly’ in Definition 3 are similar to those in Definition 1, but with an additional attention to human rights [11■]. This attention to human rights may reflect an influence from the Scottish government’s view on dementia, that PWD and their caregivers

have the rights to participation, accountability, nondiscrimination and equity, empowerment, and legality [13].

Considering the positive aspect, the observed diversity in definitions of ‘dementia-friendly’ and ‘dementia-friendly communities’ may reflect constant progression and innovation in ways of thinking of living with dementia. On the other hand, without a standard definition, it would be difficult to test, compare, and communicate ‘dementia friendliness’ across communities and settings. To embrace innovation and diversity in dementia-friendly thinking and to avoid confusion, it would be essential for everyone to make explicit their definition when joining the discourse of ‘dementia-friendly’ or ‘dementia-friendly communities’.

CORNERSTONES AND STEPS TO BUILDING DEMENTIA-FRIENDLY COMMUNITIES

Although there is no single model or template for creating dementia-friendly communities [14■], several research groups have attempted to identify the cornerstones and key steps to building dementia-friendly communities. For example, a ‘four cornerstones’ model was proposed in Crampton *et al.*’s seminal paper, *Creating a Dementia-Friendly York* [15]. The four cornerstones are (1) place (How do the physical environment, housing, neighborhood and transport support PWD?), (2) people (How do cares, families, friends, neighbors, health, and social care professionals, especially general physicians, and the wider community respond to and support PWD?), (3) resources (Are there sufficient services and facilities that are appropriate and supportive of PWD? How well can people use the ordinary resources of the community?), and (4) networks (Do those who support PWD communicate, collaborate and plan together sufficiently well to provide the best support and to use people’s own ‘assets’ well?).

In 2016, the ADI posited a similar yet different model – In addition to Crampton *et al.*’s ‘reactive’ approach featuring ‘supporting/responding to’ PWD, the ADI’s model also features a ‘proactive’ approach to actively involving PWD at ‘all stages of the community development’ [11■]. In the ADI model, the four cornerstones are first, people (involvement of PWD), second, communities (the social and physical environments), third, organizations (dementia-friendly organizations and access to appropriate healthcare), and fourth, partnerships (cross-sectional support, collective commitment, and collaboration of organizations).

Considering the key steps to building dementia-friendly communities, one successful model is the ACT on Alzheimer’s Dementia-Friendly Communities Toolkit [16,17■]. Based on the University of Minnesota Extension’s Civic Engagement and Community Readiness models [18,19], the Dementia-Friendly Communities Toolkit features four action phases that guide the adoption of dementia-friendly practices across the community: convene, assess, analyze, and act together. As of the date of this review, the Dementia-Friendly Toolkit has been successfully implemented in 48 communities across the Minnesota State [20].

DEMENTIA-FRIENDLY COMMUNITIES: PRACTICE AND RESEARCH

In 2016, the ADI released a report summarizing dementia-friendly communities in 34 countries around the world [9■]. A wide range of innovative programming and activities to create dementia-friendly communities were highlighted, including nation-specific programs such as Alzheimer Society of Ireland's project to create visual information about dementia for those with low literacy in Traveller communities [21], as well as programs that have received international recognition, such as the UK's Dementia Friends programme and the Netherlands' Alzheimer Café [22,23]. As of 2016, the Dementia Friends programme has been implemented in over 10 countries [24,25] and the Alzheimer Café in over 15 countries [23].

In addition to the ADI report, there was another multicountry report on dementia-friendly communities released in 2016 that was noteworthy [14■]. In contrast to the ADI's global focus, this report only included European countries. In addition to profiling each country's dementia-friendly communities, the report also attempted to identify commonalities and differences across countries in their approaches to building dementia-friendly communities. The four key elements identified in this study in developing dementia-friendly communities were similar to the four cornerstones' in the ADI model described earlier. This study also created a taxonomy for dementia-friendly community activity.

A number of other studies have evaluated various aspects of dementia-friendly communities, but tended to have a more local/regional focus. Smith *et al.* [10] investigated perspectives of PWD on rebuilding Christchurch, New Zealand as a dementia-friendly city postearthquake. Page *et al.* [26] identified a new concept, 'dementia-friendly tourism', within a destination context and examined supply and demand issues associated with dementia-friendly tourism in the UK. Han *et al.* [27■] synthesized 34 qualitative studies using a meta-ethnography approach to understand the perspectives of PWD on 'meaningful activities' – which are believed to help meeting fundamental psychological needs of PWD [28■]. Even though the focus of Han *et al.*'s study was only on this one aspect of community life, that is meaningful activities, the results were based on a synthesis of studies conducted in various countries. Innes *et al.* [29] investigated barriers to leisure participation for PWD and their caregivers and identified 'accessibility' as the overarching theme. Heward *et al.* [30■] evaluated an inter-agency project in the South England and interviewed project workers that were leading the community building efforts of seven dementia-friendly communities in the region. Compared to the 10 key areas that underpinned a dementia-friendly community outlined by the Alzheimer's Society, most progress had been made only within three areas: 'challenging stigma', 'accessible community activities', and 'respectful and responsive business and services'. In addition, project workers interviewed revealed that it was difficult to talk to PWD directly because caregivers would often take over the conversation and that not PWD but caregivers were involved in the community-building steering group made of local stakeholders. (These findings may suggest the existence of potential power imbalance within the PWD-caregiver dyad.) Additionally, this study also pointed out that the reliance on stakeholder involvement might lead to potential long-term sustainability issues of dementia-friendly communities. Several studies also examined citizenship in the context of dementia-friendly communities, as well as how place and environmental designs influenced resilience

and narrative citizenship of PWD and families [31■,32,33]. These investigations echoed the growing attention to PWDs human rights in defining dementia-friendly communities. Overall, these studies made important contributions to the conceptual innovation and development of dementia-friendly communities, as well as pointed out essential issues and challenges to be considered. However, these studies tended to be qualitative or exploratory by nature. Also, none of the studies has evaluated how dementia-friendly communities have impacted the health, healthcare cost, and quality of life of PWD and caregivers.

BEING DEMENTIA FRIENDLY IN HEALTHCARE SETTINGS

When applying the concept of ‘dementia-friendly’ to the context of healthcare, some researchers proposed that the care and treatment of patients should be first, appropriate to their needs and second, of an equivalent standard expected by any patient [34■,35]. According to Handley *et al.* [34■], in order to make healthcare more dementia-friendly, a number of service areas needed to be improved and kept at the same standard for any patient. These include diagnosis rates, access to care, treatment support and information, coordination of care, admission and readmission to hospital, admissions to care homes, and postdiagnosis support. The inadequacy of healthcare services for PWD, though was examined from another angle, was also confirmed in Briggs *et al.*’s recent study [36]. They found that in acute hospital settings, first, PWD accounted for 2% of all inpatient episodes and 10% of total bed days, second, PWD had twice the average length of stay compared to older adult patients without dementia, and third, PWD had nearly three times the per person average hospital care cost compared with patients without dementia. On the basis of these findings, Briggs *et al.* concluded that first, even though service activity attributable to dementia care in the acute hospital is considerable, currently services do not meet the needs of PWD adequately and second, acute hospitals need to provide a more ‘dementia-friendly’ service.

In addition to ensuring healthcare services meeting the needs of PWD and of equivalent standard expected by any patient, physical and psychosocial care environments also contribute to the dementia-friendliness of healthcare settings. For example, infrastructure and care pathways, person-centered approaches to care, how PWD interact with their environment and other patients, the inclusiveness of PWD and caregivers in care and treatment discussion and decision makings are all important factors to consider [34■,37]. To ensure the physical environment in healthcare settings is dementia-friendly, several environmental audit tools have been developed over the past few years. One recent example was the environmental assessment tools developed by theKing’s Fund in England [38■]. The assessment tools were developed for hospitals, care homes, health center, and housing with care and were proven to be effective in both disseminating the principles of dementia-friendly designs and enabling improvements that led to a positive effect on patient outcomes and staff morale. A few other dementia-friendly studies had also focused on how psychology could guide the development of dementia-friendly design guidelines and what environmental designs were important to improve end of life care for PWD [39,40]. There was also a recent study evaluating both the physical and psychosocial care environments of hospital wards in the context of dementia care [41■]. In the study, the level of dementia-friendliness of hospital wards were rated based on first, the extent to which the physical design met

dementia-friendly principles when compared against an environmental audit tool, second, staff practices and interactions with patients and the extent to which they improved or decreased well being as measured through dementia care mapping, third, staff perceptions of the extent to which the care they carried out was person-centered, and fourth, staff perceptions of the extent to which the ward culture facilitated or hindered person-centered care. Even though the study revealed that much of the physical and psychosocial care environments could be improved, the researchers concluded that with detailed recommendations and ongoing mentorship, important incremental changes could occur.

CONCLUSION

This review discussed the conceptual issues around ‘dementia-friendly communities’ and summarized important reports and research studies on ‘dementia-friendly communities’. Some important topic areas in being dementia-friendly in healthcare settings, such as an equal healthcare service standard, appropriate treatment, inclusion of PWD in decision making, and the evaluation of physical and psychosocial environments, were also highlighted.

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KEY POINTS

- Over 30 countries across the world have been working towards making their communities more dementia-friendly.
- The diversity in definitions of ‘dementia-friendly communities’ may reflect the constant innovation and progression in ways of thinking of living with dementia.
- More robust research evidence is needed to understand the community- or population-level impact of dementia-friendly communities.
- In healthcare settings, in addition to making physical and psychosocial environments dementia-friendly, it is important to ensure that people with dementia receive appropriate and needed care services kept at the same standard as any patient.

Table 1

Definitions of dementia-friendly communities

Definition #	Direct quote	Dementia friendly	Community
1.	‘A dementia-friendly community is one in which people with dementia are empowered to have high aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them [8]’. The ‘community’ in this definition was further interpreted by the ADI: ‘A dementia-friendly community is made up of individuals (representing either themselves or an organization) coming together to achieve a common goal. It can be a place (street, village, town, city, region), and organization (public, private, and voluntary), a group or even a virtual community’ [9■]	PWD; Defining attributes: empowerment, aspiration, self-confidence, contribution, participation, meaningful activities	Place, organization, a group of individuals, a virtual community
2.	‘A dementia-friendly community is one in which both the physical and social environment is responsive to the needs of a person with dementia. According to people with dementia, this includes that they can find their way around and feel safe, access the local facilities that they are used to, maintain their social networks, and people are accepting and understanding’ [10]	PWD; Defining attributes: way-finding ability, sense of safety, accessibility, maintenance of social networks, social acceptance, understanding of dementia	Physical and social environments
3.	‘A dementia-friendly community can be defined as: a place or culture in which people with dementia and their cares are empowered, supported and included in society, understand their rights and recognize their full potential’ [11■]	PWD and caregivers; Defining attributes: empowerment, support, social inclusion, rights, recognized potential	A place or a culture