



University of
Salford
MANCHESTER

Dementia friendly care : methods to improve stakeholder engagement and decision making

Innes, A, Smith, SK and Bushell, S

<http://dx.doi.org/10.2147/JHL.S292939>

Title	Dementia friendly care : methods to improve stakeholder engagement and decision making
Authors	Innes, A, Smith, SK and Bushell, S
Publication title	Journal of Healthcare Leadership
Publisher	Dove Medical Press
Type	Article
USIR URL	This version is available at: http://usir.salford.ac.uk/id/eprint/61668/
Published Date	2021

USIR is a digital collection of the research output of the University of Salford. Where copyright permits, full text material held in the repository is made freely available online and can be read, downloaded and copied for non-commercial private study or research purposes. Please check the manuscript for any further copyright restrictions.

For more information, including our policy and submission procedure, please contact the Repository Team at: library-research@salford.ac.uk.

Dementia Friendly Care: Methods to Improve Stakeholder Engagement and Decision Making

Anthea Innes 
Sarah Kate Smith
Sophie Bushell

Salford Institute for Dementia and Ageing, School of Health and Society, University of Salford, Salford, UK

Abstract: Dementia friendly (DF) is a term that has been increasingly used in the international literature to describe approaches that include and involve people living with dementia within their communities and wider society. How to support the involvement of people living with dementia to achieve dementia friendly care or support outcomes is an area that has begun to receive attention. We begin by introducing the concept of dementia friendly, the policy context and what has already been evidenced via prior reviews and conceptual discussions. We conducted a systematic review following PRISMA guidelines, resulting in the inclusion of nineteen papers that reported on the methods and approaches used to involve people living with dementia in achieving dementia friendly or supportive care outcomes. Five primary themes were identified: the potential of group-based activities to facilitate inclusion and engagement; achieving engagement in decision making; the value of developing tools to help service providers to engage those living with dementia in care decisions; the role of awareness raising and education to support the inclusion of a range of stakeholders in achieving DF support and care outcomes; the need for cultural and contextual sensitivity when seeking to engage stakeholders to achieve positive care outcomes. We conclude by considering how both the underpinning ethos of social citizenship and social inclusion need to be in place alongside a range of approaches that are adapted to fit local contexts and needs to enable the involvement of people living with dementia in achieving dementia friendly care outcomes.

Keywords: people living with dementia, involvement, supportive communities, inclusive, social citizenship

Introduction

Global prevalence of dementia is high (50 million people currently)¹ and is projected to double every two decades until 2050.² Policy has set the directive to achieve outcomes that are “dementia friendly”^{3,4} with UK⁵ and international examples of dementia friendly initiatives now available.⁶ Dementia care is complex, and self-managing dementia and navigating dementia care is challenging; therefore what dementia friendly agendas mean for the practice of dementia care is similarly complex and challenging.

In the UK, the term dementia friendly was first used explicitly in government policy in 2012³ in the Prime Minister’s Challenge on Dementia, where the creation of dementia friendly communities was stipulated as a government aim. Thirty countries have since been identified as working towards making their communities dementia friendly.⁷ In their review, Hebert and Scales⁸ identify many strands to what they term dementia friendly initiatives, including: dementia awareness

Correspondence: Anthea Innes
Salford Institute for Dementia and Ageing,
The Dementia Hub, School of Health and Society,
University of Salford, Salford, UK,
M6 6PU
Tel +44 0161 295 2363
Email a.innes1@salford.ac.Uk

education, environmental design and dementia friendly community developments. They identify both a lack of theory-based studies, although most research they reviewed appears to have person-centred principles underpinning the work, and also the relative absence of the views of people living with dementia in what is a developing and, as previously noted, a primarily qualitative research base.⁷ Importantly this paper does not focus solely on dementia friendly care and methods to include stakeholders, but on any initiative that could be considered to include “dementia friendly” elements of work. For this paper, stakeholders are people living with dementia, care partners (family members) and care commissioners and providers.

In a review of the concepts guiding dementia policy, via national plans, frameworks or strategies, Lin and Lewis⁹ identify three core concepts offering ways forward for dementia policy, practice and research. Two have emerged from policy directives, as already noted: Dementia Friendly from the UK government (although there are UK regional variations with Dementia Supportive preferred) and, from the US dementia action plan, Dementia Capable; Lin and Lewis⁹ add a third concept, Dementia Positive, that they coined from their review of the literature into the first two areas of work. The change in the language surrounding dementia is notable in the last decade⁸ and offers a roadmap towards what the World Health Organization and Alzheimer's Disease International¹⁰ called the normalization of dementia within society. Lin and Lewis⁹ argue that “dementia friendly” has at its heart a desire to include and involve those with lived experience of dementia, while “dementia capable” involves acknowledging dementia as a disability and mobilizing support and services to then promote the inclusion of people living with dementia in society as part of the disability inclusion movement. They argue that without the language of dementia positive, “defined as positivity towards dementia with an intentional emphasis on strength finding, manifesting through attitudes, beliefs, communications, and behaviors”,⁹ then the goal of inclusion and normalization will be challenging to achieve. It is against this acknowledged backdrop of a change in focus and terminology, what we are calling “dementia friendly” in this paper, that our review is situated. We know that there is a change in policy directives, but what methods or techniques do we have knowledge of to achieve the involvement and inclusion of people living with dementia in the outcome of dementia friendly care or support? The focus on achieving outcomes for those living with dementia by applying the concept of dementia friendly to healthcare

has been reviewed by Lin,⁷ who argues that the inclusion of those living with dementia is one way to achieve dementia friendly healthcare settings, as are environmental design and appropriate services. Our review focuses on the former, namely methods to ensure the inclusion of people living with dementia, as our aim is to explore the methods that can be used to achieve dementia friendly care outcomes.

It is important to also recognize the related literature that seeks to include people living with dementia. Supported decision making, or shared decision making, is one way people living with dementia can be enabled to direct their care and support needs and as such is an example of dementia friendly care in action and has been the subject of recent reviews. In their review, Wied et al¹¹ found examples of methods and techniques to implement the policy directives of human rights via supported decision making. These include strategies that create a conducive environment for supported decision making and strategies that recognize the strengths and abilities of the person and avoid deficits (for example, times of day when the person is less cognitively alert). In this way this review demonstrates ways that the basic and fundamental principles of human rights declarations can be applied to support the decision-making processes in assessing and implementing the care and support needs of individuals with dementia. Similarly, the review by Geddis-Regan et al¹² aimed to identify interventions to achieve shared decision making. They found limited examples relating to feeding decisions and advance care planning as well as studies that suggested techniques to enhance communication to enable shared decision making to occur. This is important, as emotion influences the everyday decision making of people living with dementia, yet another review¹³ found little evidence around how to help regulate emotion to enable decision making and promote the wishes of those with the diagnosis in everyday care decisions around social care planning and finances. While not focused on dementia friendly outcomes per se, these three reviews^{11–13} demonstrate the possibilities that finding ways to enable the involvement of people living with dementia in decision making may have for achieving DF care.

Another important area for achieving dementia friendly outcomes is maintaining social connections. In their review, Birt et al¹⁴ found that the support of others is required to enable the individual with dementia to maintain social connections and also through a range of personal strategies that individuals with dementia use to sustain their connections, including conforming to expected norms in social situations. In this way the social reserves and

competencies of people with the diagnosis are required to navigate and maintain connections, but others can also help support this process. Thus, a key element of dementia friendly care is both recognizing the individual agency and strategies people with the diagnosis employ to achieve DF outcomes, but also the critical role others have in supporting this process. A scoping review¹⁵ demonstrates the possibilities, as yet under-researched and difficult to evaluate, that engaging in the arts may have for achieving what would be broadly aligned with “DF” outcomes for those living with dementia via social inclusion and connection.

Creativity has been discussed as a method to engage those living with dementia. Bellass et al¹⁶ have argued that creativity needs to be understood not just as partaking in traditional cultural arts practices but also as something that takes place in the everyday. This broader understanding of everyday creativity allows for new insights into the lives of people living with dementia while also advocating for relational approaches to creativity as opposed to “individual” approaches which can erase the relationship that the person has with their creative work.

The concept of social citizenship¹⁷ as a lens to understand dementia has gained increasing popularity in the movement towards advocacy and autonomy of people living with dementia. This shift in focus has been important and includes the individual’s participation and inclusion in care, research and governance. Contributing to the development of a citizenship model from an organizational studies perspective, Baldwin and Greason¹⁸ discuss citizenship as a practice – something that is realized through action and in relationship to others. Introducing the concepts of midi- and micro-citizenship, the authors suggest a means to build citizenship alliances between people with dementia living in long-term care (LTC) facilities and front-line dementia care staff.¹⁸

Examples of involving people living with dementia/stakeholders in research abound.^{19–23} These papers have highlighted several important issues relating to the increasing awareness of the importance of user involvement for dementia research. Challenges include finding ways to provide people living with dementia an equal opportunity to be involved, how to reach diverse groups of people living with dementia, how to provide the necessary support when we do reach those groups and how to maximize the potential of people with dementia to contribute towards research.²³ Although the review papers we have contextualized our discussions within illustrate the plethora of evidence regarding people living with

dementia and their effective involvement in research, examples of involving people living with dementia/stakeholders to achieve dementia friendly care are less obvious and more limited. This paper focuses on examples of methods and techniques to involve stakeholders, particularly people living with dementia, in achieving dementia friendly or dementia supportive care outcomes. We also build on key concepts that shape what might be considered dementia friendly, as well as the dementia friendly literature itself.

Methods

We conducted a systematic review following PRISMA guidelines.²⁴ PRISMA seeks to improve the reporting of systematic reviews and meta-analyses through the use of checklists and flow diagrams (see Figure 1). The PRISMA checklist was used to explore the characteristics of each included study focused on the aims, methods, findings, conclusions as well as our consideration of the implications of the study for dementia friendly care or support outcomes. As this systematic review was not registered, we cannot provide a registration number. A review protocol was not prepared.

Search Strategy

Electronic databases, MEDLINE (Health Care Systems, Nursing databases), Cumulative Index to Nursing & Allied Health Literature (CINAHL), PsycINFO (Psychology, Medicine, Psychiatry, Nursing, Sociology, Physiology and Linguistic databases), ProQuest Central (including Health and Medical, Social Sciences, Education and Humanities databases), OVID Online (Medical and Health Databases) were searched between 15th and 19th February 2021 using the search terms described in Table 1.

The search was limited to English-language studies published between 2000 and 2021. The rationale for the selected time period (2000–2021) was to capture any work prior to the time period of when the term dementia friendly became popular in policy and practice developments from 2009; however, very little work relating to dementia friendly was found before 2009. We used the terms Stakeholder Engagement OR User Involvement OR PPI in an attempt to reduce the vast quantities of original “hits” that appeared when using search terms like “participant” and “consumer”. Specifically, “participant” gave rise to many papers involving research participants and not evidence of stakeholder

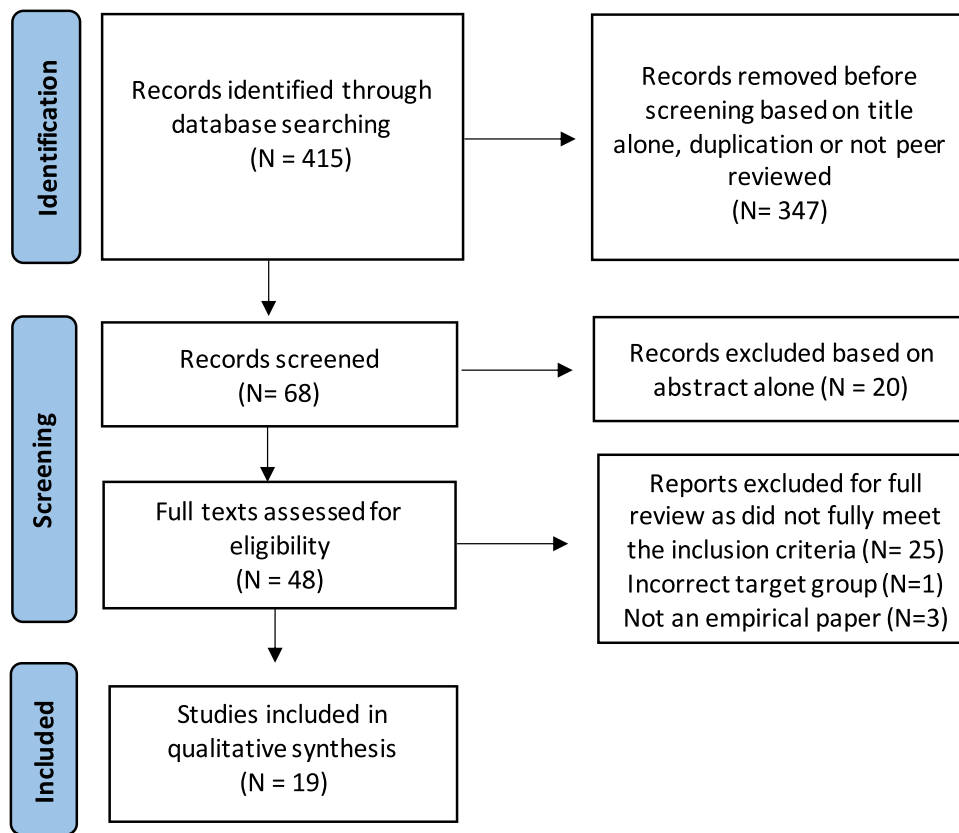


Figure 1 Flowchart displaying study selection according to PRISMA.

engagement or involvement which were essential search terms from the title for our review purposes.

Inclusion Criteria

Only published peer-reviewed original empirical articles were considered for inclusion. Excluded from review were dissertations, editorials, book chapters, book reviews, letters to

editors, position papers, conceptual discussions and commentaries.

Data Extraction

After duplicates were removed, two reviewers (authors 1 and 2) conducted two independent screenings. First, the titles were screened, and then the abstracts of the remaining articles. Included papers for review were distributed equally between authors 1, 2 and 3 for data extraction. This third screening consisted mainly of one reviewer reading full-text articles (all three authors) with papers reviewed by a second member of the writing team when it was considered by the first allocated reviewer that the paper did not fit our inclusion criterion when read in full. This led to 6 fully reviewed papers being subsequently excluded. Extracted data were then verified by authors 1 and 2 and included details regarding the sample, study aims, setting/context, findings, conclusions and implications.

Findings

The database search resulted in 415 potentially relevant articles identified for review; 347 were immediately excluded based on title alone, duplication or not from

Table 1 Search Terms

Dementia OR Alzheimer's disease (AD)	NOT pharmacological OR drug trials OR clinical evaluation/assessment OR neuroimaging
Stakeholder engagement OR user involvement OR PPI	NOT pharmacological OR drug trials OR clinical evaluation/assessment OR neuroimaging
Dementia friendly care OR dementia care OR dementia friendly	NOT interventions for carers
Decision making	NOT decision modelling
Social citizenship OR activism OR human rights	NOT animal rights OR drug trials

peer-reviewed journals. Author 1 and 2 each reviewed half of the remaining 68 abstracts, and 20 further articles were excluded based on the abstract alone. After reviewing the abstracts, 48 full PDFs were extracted for review that met the inclusion criteria. Of the remaining 48 studies that met our inclusion criteria, 23 were further excluded from full review, as they did not meet the inclusion criteria. Twenty-five papers were fully reviewed, but on detailed reading a further six did not fully meet our criteria, thus the remaining nineteen studies are included in the present review that focus on dementia friendly care: methods to improve stakeholder engagement and decision making.

Table 2 presents the nineteen included studies that have been reviewed using 7 column headings: Lead Author and Date, Country and Setting, Methods and Participants, Aims, Findings, Conclusions and Implications for Future Involvement of People Living with Dementia (PLWD)/ Stakeholders to Achieve Dementia Friendly Care.

All studies included in the review focused on dementia friendly care and methods to involve stakeholders. Ten studies adopted a purely qualitative approach,^{25,27,30,33–35,38,39,41,42} with nine using mixed methods.^{26,28,29,31,32,36,37,40,43} The majority of articles ($n=12$)^{25,27–30,33–35,37–39,42} included multiple stakeholders, including those living with dementia; there were three studies^{26,32,41} including only people living with dementia, and others solely focused on other stakeholders, for example employers ($n=1$),⁴³ caregivers ($n=1$)⁴⁰ or health and social care professionals ($n=2$).^{31,36} The papers reviewed were drawn primarily from Canada ($n=6$),^{25–29,41} and the UK ($n=5$),^{35,36,38,42,43} with others from Ireland ($n=2$),^{31,32} Australia ($n=2$),^{30,37} the USA ($n=1$),⁴⁰ the Netherlands ($n=1$),³³ Sweden ($n=1$)³⁴ and Taiwan ($n=1$).³⁹ Most studies ($n=15$)^{25–27,29–31,33–35,37–40,42,43} focused on engaging and including those living in the community (which included two studies focusing on attending day provision or clinics within a hospital^{35,39}), two studies focused on care homes settings^{28,32} and two focused on the hospital setting.^{36,41}

A thematic analysis of the implications drawn from each paper (final column of Table 1) reviewed was undertaken. Author 1 identified the thematic areas, and authors 2 and 3 verified these. Five thematic areas emerged from our review.

The Potential of Group-Based Activities to Facilitate Inclusion and Engagement

Canadian-based studies exploring group-based activities demonstrated how social inclusion, social citizenship and partnership working principles could be enacted with

reported positive benefits for those living with dementia^{25–29} in terms of fostering feelings of belonging and value but also in day-to-day decision making and choices. Work by Theurer et al²⁸ demonstrates how groups (a music group) have been developed for use in long-stay care settings that promote inclusion in creative ways, while the work of Dupuis et al²⁵ for community-dwelling people living with dementia also demonstrates how participation in a creative group helps to challenge perceptions of a lack of ability by showcasing what is still possible while living with dementia. The study by Phinney et al²⁷ exploring a community group for people living with dementia demonstrates the value of normal day-to-day activities in the neighbourhood to enable the enactment of social citizenship via interactions with neighbours, children and pets. The role people living with dementia can play in driving the direction of support is set out in the work of Wiersma et al²⁹ and Mann²⁶ who set up advisory hubs and an advisory group, respectively, where people living with dementia can work together to help agree and advocate for the direction of support they might need in the future. In these ways, groups offered a conduit to reaching principles that underpin dementia friendly care agendas.

Achieving Engagement in Decision Making

Five studies we reviewed recognized the importance of involvement in decision making about care to achieve positive DF outcomes. The Alzheimer Society of Canada Charter of Human Rights, developed with people living with dementia,²⁶ demonstrates the desire for those with the dementia diagnosis to play an active part in all decision making relating to their lives and how by working in partnership together they can achieve collective advocacy to shape future decisions about dementia care. How to achieve shared decision making in practice can be challenging for care professionals. Examples of attempts to address this in care practice by professionals can be found in Australia,³⁰ the Netherlands³³ and Ireland.^{31,32} Groen-van de Ven et al³³ found that shared decision making with people with dementia was possible, but that it required an adapted process. Giving potential service users and their families the opportunity of trying out services before committing to use them was one way of achieving this. In Ireland,³² steps to involve people living with dementia at home in their care planning decisions suggests that advocacy could have a useful role in helping social workers to take forward the expressed wishes of those

Table 2 Summary of Papers Reviewed

Lead Author and Date	Country and Setting	Methods and Participants	Aim	Findings	Conclusions	Implications for Future Involvement of PLWD/ Stakeholders to Achieve DFC
Bennett ⁴² 2019	UK. Diagnostic clinic	Qualitative, semi-structured interviews with 14 participants (3 specialist nurses, 1 support worker, 5 “patients”, 5 “companions”). Focus group involving “service recipients” (2 PLWD), 7 “service deliverers” (managers, nurses, support workers).	To develop a tool specific to dementia diagnosis delivery.	Experience of diagnostic delivery for PLWD and clinicians reported. Barriers to good delivery were long wait times and rushed delivery. Suggested improvements were: develop supportive relationship, promote choice, develop understanding, provide emotional support. 2 tools were developed including the PLWD perspective to support diagnostic delivery.	Provided insight into the experience of diagnostic delivery for clinicians, PLWD and CP. These tools can help to improve the diagnostic delivery experience of PLWD and clinicians.	Such tools might offer an improved dementia diagnosis process by encouraging and supporting PLWD to prepare. Such a process may be more “dementia friendly” for all involved.
Buckner ³⁸ 2019	Dementia friendly communities (DFC) across England.	Scoping study involving 284 DFC initiatives.	To describe the characteristics of DFCs across England to inform a national evaluation of their impact on the lives of those affected by dementia.	Among DFC activities, awareness raising was cited most commonly, some evidence of involvement of PLWD in organizational and operational aspects of DFCs. Approaches to evaluation varied, little evidence of findings having effected change.	DFCs are characterized by variation in type, resourcing and activities. England has policy endorsement and a recognition system for DFCs. These can be important catalysts for initiation and growth.	To gain a better understanding there is a need to move beyond description of what is “good” DFCs to include different settings and for different populations (rather than consistent self-selecting).
Donnelly ³¹ 2019	Ireland. Involvement of PLWD in care planning.	Online survey of social workers working with older adults (n=38). In-depth interviews with social workers (n=21) (separate cohort). Social workers working with older adults (n=59).	To explore how older people with dementia participate in decision making about their care.	Predictors of care involvement amongst PLWD: capacity, paternalistic approach from family members, need to balance risk and autonomy (family members and professionals often cautious and risk-averse) – SWs can be critical advocates for decision making.	Supported decisions will only become reality if effective systems are put in place. PLWD should be encouraged to participate in decision making about their care.	Advocacy offers opportunities for PLWD to be involved in decision making about their care and support. Being dementia friendly is about giving PLWD choice and control, including choice and control to take risks.

(Continued)

Table 2 (Continued).

Lead Author and Date	Country and Setting	Methods and Participants	Aim	Findings	Conclusions	Implications for Future Involvement of PLWD/ Stakeholders to Achieve DFC
Dupuis ²⁵ 2016	Canada. Community-based, critical arts project.	Creation of a research-based drama challenging the tragedy discourse of dementia. Focus groups and artistic reflection co-created with PLWD. Telephone interviews PLWD (n=8), family members (n=7), performance artists (n=15), researchers (n=7).	To provide PLWD a creative opportunity to challenge dominant and oppressive master narratives. Enable the emergence of emancipatory stories.	Narrative citizenship offers an informative way to fashion new discourse of citizenship and dementia.	When PLWD were able to interrogate negative discourse, stigma and stereotypes their meaning lost significance and opened up alternative discourses of possibilities through mutual story telling.	Using drama to challenge the negative discourse of dementia. This approach has the potential to be used in a wider context in the community.
Egdell ⁴³ 2021	Scotland UK. Employers' perspectives.	331 responses to online employers' survey and 30 follow-up employer interviews.	Employers' views on dementia as a workplace concern and the policies and practices available to support human rights agendas for PLWD.	Dementia awareness was found, but this knowledge was not applied to employment situations. Lack of evidence that the rights of employees living with dementia are consistently upheld.	The rights and legal position of working age PLWD need addressing as they are consistently not recognized.	There is a lack of application of awareness of dementia to the workplace setting, and therefore training for employers is needed to support future action.
Goeman ³⁰ 2019	Australia. Community setting.	Evaluation study, expert working group and reference group of unspecified numbers of people living with dementia and care partners, aged care service providers, policymakers; and academics.	To describe the co-design process.	The development of a successful co-design process that includes PLWD and care partners at all stages of the research process and addresses their individual needs.	Co-design provides support for community-dwelling people to be involved in the research design, dissemination and implementation of the findings.	Involving PLWD and care partners in co-designing research projects ensures that services/models/ future research reflect the expressed views and opinions of the consumers.
Grace ³⁷ 2018	Australia. Social group.	Co-designed workshops to develop dementia support toolkit. Involved 8 PLWD and carers, 13 members of local older people social groups and 22 local GPs and other health-service providers.	To evaluate a dementia health literacy project.	A dementia support kit was produced to provide locally relevant and useful information for people with dementia and their carers.	Co-design is a valuable approach to producing and disseminating dementia health literacy resources.	Such tools may have implications for future behaviours and health outcomes.

(Continued)

Table 2 (Continued).

Lead Author and Date	Country and Setting	Methods and Participants	Aim	Findings	Conclusions	Implications for Future Involvement of PLWD/ Stakeholders to Achieve DFC
Groen-Van De Ven ³³ 2017	Netherlands. Community settings and nursing homes.	Qualitative, prospective, multi-perspective, via 244 interviews 19 people with dementia (early-moderate), 36 of their informal caregivers and 38 of their professionals (including nurses, day-care employees and case managers).	To explore how people with dementia, their informal caregivers and professionals participate in decision making about day-care and to develop a typology of participation trajectories.	Critical points were expectations of day-care, negotiating trying out day-care, trying out day-care. Participatory trajectories were working together positively towards day-care, bringing conflicting perspectives together to facilitate trying out day-care and not reaching a commitment to try out day-care.	Shared decision making with people with dementia is possible and requires an adapted process of decision making; trying out services one way of achieving this.	Finding ways for people to “try out” care solutions can enhance involvement in decision making and DFC outcomes.
Guest ⁴⁰ 2021	South Carolina, USA. Caregivers providing support to people living in the community.	148 African-American caregivers participated in education intervention, were trained and completed pre- and post-test questionnaire. 34 were interviewed.	To evaluate the impact of a pilot education programme – In Our Community, Dementia Speaks.	Information on caregiver practice, caregiver strategies, caregiver quality of life and patient quality of life.	Community members reported the programme a success in further engaging African-American caregivers of individuals living with dementia and the need for the programme to be revised and expanded.	Cultural norms are important – tailoring an education intervention is one way of engaging more family caregivers.
Mann ²⁶ 2020	Canadian charter of rights for people living with dementia.	Conversations amongst Alzheimer Society of Canada’s advisory group members (PLWD 8).	Aim to create a charter to be a tool to challenge stigma and increase awareness of dementia and its links to human rights.	Charter of rights: To be free from discrimination of any kind. To benefit from Canada’s civil and legal rights. To get information and support to participate fully in decisions.	The rights of PLWD should be recognized, and people (such as medical teams and care staff) should be made aware of this charter.	Demonstrates that PLWD can work together to advocate for their own rights if provided with appropriate support.
Mayrhofer ³⁵ 2018	Community-based services in 2 UK sites.	Discussion groups with PLWD, interviews with memory services and other service providers. Involved 31 PLWD, 3 memory services and 7 local service providers.	To understand priorities for service planning and commissioning.	Discussions confirmed published evidence on support requirements, but also reframed priorities for support and suggested new approaches to dementia care at the community level.	Involving people with young-onset dementia in the assessment of research findings provides a future way for co-designing accessible services.	People living with young-onset dementia can provide critical opinions and perspectives on research findings, service provision and future policy and research priorities. How to develop this approach is key.

(Continued)

Table 2 (Continued).

Lead Author and Date	Country and Setting	Methods and Participants	Aim	Findings	Conclusions	Implications for Future Involvement of PLWD/ Stakeholders to Achieve DFC
Morgan-Brown ³² 2018	Ireland. Care homes.	Observational study design in 5 long-stay residential units involving 73 PWLD, recording engaged and non-engaged behaviours using an audit tool.	Evaluation of the Assessment Tool for Occupational and Social Engagement (ATOSE) and development of definition of minimal acceptable levels of resident engagement.	Low levels of engagement amongst PLWD in communal areas of residential care. ATOSE provided a simple-to-use assessment of engagement and can be used as an audit tool to assess engagement.	Highlights the needs and the human rights of residents with dementia to engage in everyday occupations and social networks.	Not only are there implications for the rights and needs to engage and involve people living with dementia in care homes, but also there is a lack of tools to measure whether attempts to do so are successful.
Österholm ³⁴ 2016	Sweden. In clients' own homes.	Qualitative analysis of transcripts from 11 PLWD, assessment meetings with social worker alongside complementary ethnographic field notes.	Investigate ways PLWD practise their citizenship in assessment meetings with social workers.	Participation of PLWD in assessment meetings varies. Communication problems occurred in all 11 meetings, eg, word finding, understanding and making use of information. Other difficulties included keeping up with conversation, remembering previous happenings and repetition.	An individual's dementia may affect their ability to contribute to assessment meetings and thereby practise their citizenship.	Further studies are needed to look at communication styles amongst social workers and see if and how using alternative styles can promote participation.
Parke ⁴¹ 2017	Canada. Hospital settings.	Exploratory iterative design utilizing scoping literature review methodology exploring DF design.	To report the findings of a knowledge synthesis research project on the topic of dementia friendly acute care (D-FAC) design.	Confirms the limited nature of available acute care design evidence on maximizing function.	Physical design influences the usability and activity undertaken in a health care space and ultimately affects patient outcomes.	Knowledge about how design influences PLWD in hospital spaces is still lacking. Even more can be learnt from PLWD themselves, but this is not indicated in this review.
Phinney ²⁷ 2016	Canada (BC). Community group (social/leisure) for younger people (Paul's group).	Ethnographic: 400+ hours of participant observation over 58 sessions, fieldnotes/go-along (walking) interviews, walking vignettes/FG and data from family member interviews; 12–15 PLWD.	To explore how community-based programming can promote social citizenship for people with dementia.	The group, particularly the walking excursions, is an act of social citizenship by: 1. Keeping the focus off dementia; 2. Creating a place of belonging; and 3. Claiming a place in the community.	A focus on "normal" leisure-based activities within the community in a natural way. Focusing on what people can and want to do enables social citizenship to be enacted in the community. Positioning, participation and community key concepts.	Offers a way to contribute to DF communities through involvement and enacting of social citizenship via engaging within the local community walkways. Suggests an alternative to traditional care provided by health and social care professionals to enable the involvement and inclusion of people with dementia (who are relatively well and physically able).

(Continued)

Table 2 (Continued).

Lead Author and Date	Country and Setting	Methods and Participants	Aim	Findings	Conclusions	Implications for Future Involvement of PLWD/ Stakeholders to Achieve DFC
Theurer ²⁸ 2014	Canada (BC). 3 long-term care homes (LTCH), Java music club (mutual support group).	Mixed-methods qualitative process evaluation design: focus groups, systematic observation of six resident groups, individual resident interviews (<i>n</i> = 65) and staff interviews (<i>n</i> = 7) of those involved in the Java music group.	To present and describe a rationale for an intervention involving mutual support groups in LTCH; to evaluate its process, structure and content; and to provide evidence that supports refinement and replication. Based on enacting Kitwood model of personhood.	Group structure fosters active participation of residents with moderate–severe cognitive impairment.	This preliminary study suggests that mutual support groups (in this case a music-based group) have potential to offset loneliness, helplessness and depression within LTCH. Also increases opportunities for the voices of people with dementia in LTCH to be heard and for the focus and direction to be based on resident wishes rather than staff.	Mutual support groups (based on the Java music group model) provide a way to achieve dementia friendly care outcomes by increasing self-determination by taking on leadership and making choices; increasing giving and receiving help, increased focus on inner strengths, beliefs and abilities, strengthen supportive relationships with one another and to increase expression of challenges faced allowing interpretations.
Waller ³⁶ 2017	UK. NHS Trusts.	Development, use and review of environmental assessment tools in hospital wards, care homes, health centres and housing with care.	To develop more supportive design for people with dementia in hospitals.	10,000 copies of the tools have been downloaded, for use in hospitals, care homes and hospices across the UK, Australia, Scandinavia, Holland, Germany, Brazil, Canada and the USA.	Using the tools led to securing finance to make environmental changes. The tools were valued in supporting attitudinal change and enabling DF design in refurbishment.	The authors imply that getting physical design right for people with dementia is also likely to enhance the experience of those who live, work and visit a care environment.
Wiersma ²⁹ 2016	Canada. Community.	Participatory action research (PAR) using 3 advisory hubs. 3 hubs comprising 20 people with dementia, 13 care partners and 3 service providers, in 3 locations across Canada.	To develop a self-management programme for people with dementia (grounded by a citizenship lens).	Group composition was important (to include care partners or not). 4 themes around this core issue: creating safe spaces; maintaining voice and being heard; managing the balancing act; and the importance of solidarity. A fifth theme, the recognition that “one size doesn’t fit all”.	Participating in groups with other PLWD can be liberating, empowering and build confidence, providing opportunities for growth, change and development. A focus on “living well” and “self-management”, a sense of solidarity with others can be transformative.	To support social citizenship (an outcome of DFC) of people with dementia, researchers and practitioners must pay attention to these dynamics between people with dementia and care partners and understand the implications of groups participating separately or together.

(Continued)

Table 2 (Continued).

Lead Author and Date	Country and Setting	Methods and Participants	Aim	Findings	Conclusions	Implications for Future Involvement of PLWD/ Stakeholders to Achieve DFC
Wu ³⁹ 2018	Taipei, Taiwan, people living in community attending day-care or neurological centre.	Qualitative interviews with 16 people with dementia and 20 family caregivers.	To identify dementia friendly communities' indicators and their current conditions in Taiwan from the perspectives of people with dementia and dementia family caregivers.	Found 8 DFC indicators: DFC services; DF hospital; DFC environment; DF transportation; DF stores and shops; DFC members; integrated dementia-related information; and opportunities for PLWD to contribute and be involved in the community. Inclusion of those with dementia not expressed as strongly. 1 PLWD and 5 carers expressed desire for PLWD to be included in the community activities.	Involvement of people living with dementia was not expressed by participants. Strategies to try and involve people are needed (but they do not say what these might be). Also need for comparative research that takes into account different cultural contexts.	Importance of wider cultural norms and understandings of dementia evidence. Suggests stigma more prevalent in Asian countries and more work to do to raise awareness. Also suggests age friendly might be way forward, things that enable all older people to be active participants in society and remove the focus on dementia.

Abbreviations: CP, care partner; PLWD, person living with dementia; DF, dementia friendly; DFC, dementia friendly care; D-FAC, dementia friendly acute care; LTCH, long-term care homes.

with dementia as part of the decision-making process. However, research has also found³³ low levels of engagement in care homes that need addressing before any attempts to create opportunities for shared decision making are possible. Swedish research³⁴ demonstrates the need to address the communication styles of social workers to enable better discussion and therefore involvement of the person living with dementia in care decisions. In the UK, people with young-onset dementia were asked to help evaluate service commissioning and provision.³⁵ Involving people at an early stage in the service provision process, younger or older, clearly offers an opportunity for enhanced involvement in decisions on care and support.

The Value of Developing Tools to Help Service Providers to Engage Those Living with Dementia in Care Decisions

Just as group participation could foster an engagement in decision-making activities, the development of tools in different settings to assist health professionals and others involved in supporting the person with dementia is also

a method to promote engagement³⁶ as well as a way to measure successful care outcomes.^{38,43} Clinicians and health and social care workers could therefore benefit from tools designed to promote engagement and involvement of those living with dementia, such as Grace and Horstmann's³⁷ work to develop a tool that can be used to promote dementia literacy in Australian care settings (and arguably in other countries). But also, as Buckner et al³⁸ suggest, tools offer one way to help ascertain if the care and support offered deliver DF outcomes for those living with dementia and, as Bennett et al⁴³ suggest, may help to improve the experiences of the diagnostic process for those suspected of having dementia as well as the clinicians involved in diagnosing.

The Role of Awareness Raising and Education to Support the Inclusion of a Range of Stakeholders in Achieving DF Support and Care Outcomes

Studies focusing on dementia friendly initiatives in the UK³⁸ and Taiwan³⁹ demonstrated the need for raising awareness of dementia within society as a whole, for the

goal of achieving better outcomes of those living with dementia to be a reality. Initiatives designed to provide education, such as Guest and Smith's⁴⁰ presentation of work designed to enable caregivers to support their loved one with dementia, similarly, demonstrate the benefits of increasing knowledge to enable DF outcomes for the person living with dementia. Research⁴³ also demonstrates a need for education for employers to support workers with dementia, and also by implication employees with care-giving responsibilities, for the principles of human rights, as they apply to the DF movement, to be protected. Thus, awareness raising and education offer a route to improving knowledge that may then change practices that better support people living with dementia in the future.

The Need for Cultural and Contextual Sensitivity When Seeking to Engage Stakeholders to Achieve Positive Care Outcomes

Engaging caregivers from African-American backgrounds required cultural sensitivity,⁴⁰ and as Wu et al argue³⁹ it is important to appreciate wider cultural norms and understandings of dementia where lack of awareness and understanding of dementia is prevalent. This implies a need for contextual sensitivity. This might be cultural, as in the study by Wu et al in Taiwan, including the culture of care in hospitals^{36,41} where it may not always be the norm to seek to involve and engage those with dementia. It is important therefore to recognize that cultural sensitivities are particularly important when implementing programmes in multi-cultural or cross-cultural settings, or more broadly when any sort of programme is implemented in a different culture or context to that in which it was developed. Focusing on enabling design features in different physical settings, whether hospital or care homes,^{36,41} may provide a practical way to enable greater engagement and participation in the day-to-day life of a care service facility for patients and residents who are accessing such services, which in turn could lead to greater involvement in dementia friendly care outcomes.

Discussion

The main aim of this review was to summarize empirical studies involving people living with dementia and other stakeholders and how to achieve dementia friendly care.

It should be noted that in papers reviewed there was a lack of common language in discussion around engaging and involving people and also what it means to

meaningfully include or involve different stakeholders. Groups designed to support DFC outcomes have many names; for example, in articles from Canada alone, different terms were found for groups designed to help facilitate inclusion and engagement, namely Mutual Support Groups (Java Music Group),²⁸ Advisory Hubs,²⁹ Community-Based Programming (Paul's Club)²⁷ and Advisory Group.²⁶

Our review suggests a need to focus on the types of methods that can be used to involve and include people living with dementia in achieving dementia friendly care outcomes. Groups can be used to mobilize personhood, social citizenship by empowerment and social inclusion in various guises.^{25–29} This raises practical questions about types of group, who should be a member, how to facilitate, how to involve and how to monitor and evaluate. In addition, practitioners can be creative in how they seek to achieve shared decision making that may achieve dementia friendly care outcomes for those living with dementia. How to engage stakeholders to achieve involvement in decision making has been argued as a way to achieve positive outcomes that we would see as dementia friendly. Trying out care solutions is one way to involve PLWD and care partners in decisions that can lead to DFC outcomes,³³ as is a focus on creating enhanced communication opportunities.³⁴ Adopting co-design approaches not only provides support for people living with dementia to be fully involved in the research design, but also ensures the outcomes meet the needs of the population intended.³⁰ Thus, achieving involvement in dementia friendly outcomes may have similar methods to those outlined in the research methods literature seeking to operationalize core principles to involve people living with dementia in research.^{19–23}

The review demonstrates the need for tools and measures^{37,38,43} to assist health professionals in facilitating the inclusion of stakeholders, including those with dementia, both as a practical way to involve people,²⁰ but also to measure the success of involvement³⁸ in terms of outcomes. It has also been suggested that tools offer a way to raise awareness and engagement.^{37,44} This mirrors research seeking to find frameworks and approaches to standardize involvement.^{19,21} Future work seeking to explore dementia friendly care therefore needs the frameworks informed by principles of social inclusion, shared decision making^{11,12} and citizenship,^{9,17,18} but also practical work to help practitioners know when initiatives are successful.⁷

Cultural differences in terms of emphasis on involvement of PLWD may link to cultural norms and values and awareness of dementia,^{39,40} in particular communities such as younger people who may have distinct needs,³⁵ or have not accessed information about dementia easily before.⁴⁰ The context where the person lives is also important; creating environments that maximize opportunities for participation has been the focus of hospital-based research,^{36,41} while methods to involve people living in care homes also pose distinct challenges.^{32,33}

Creative methods have been proposed in earlier reviews,^{15,16} and our review found two particular examples of group work using creative methods,^{25,28} bearing out the potential of this approach. However, other approaches, such as education interventions, are also another way of providing the tools to promote inclusion and dementia friendly outcomes as was argued by Hebert and Scales.⁸ Our review found education as one successful way of engaging caregivers, with appropriate cultural sensitivity for African-American caregivers,⁴⁰ and in Scottish research a suggested approach for providing the appropriate knowledge to employers⁴³ and other health care professionals and the general public.³⁸

There are therefore many facets to how we might further define and, most importantly, achieve the goals of dementia friendly care policy directives^{3,4,6} for people living in the community or in care settings.⁷ Knowledge is growing regarding how the concept of dementia friendly^{8,9} may be operationalized and also measured, but further work is required to give a full picture of dementia friendly care in practice in different cultures and contexts.

Limitations

Our findings must be considered in terms of the limitations of the included studies (nineteen only) and the review process we followed. Some relevant studies may not have been captured by the database searches or were published after the search date. The included studies were often examples of novel initiatives in particular settings and countries. The ability to generalize findings from the studies included is therefore limited. However, the studies reviewed do clearly link to conceptual and policy developments relating to “dementia friendly”, and, as such, they help to advance knowledge in an area of dementia friendly research, care and support that has been limited to date. The need to include people living with dementia in achieving dementia friendly care outcomes mirrors

findings about the need for greater involvement of people living with dementia in the research process.

Conclusion

Engaging and including people living with dementia, and other stakeholders, in the quest for dementia friendly care outcomes is perhaps a natural progression from dementia friendly initiatives designed to achieve greater inclusion and integration of those living with dementia within their communities and society as a whole. Social citizenship and social inclusion are useful concepts, but they need to be operationalized within a range of approaches that are adapted to fit local contexts and needs to enable the involvement of those with dementia in achieving dementia friendly care outcomes. This review demonstrates that different methods may help attain the goal of involving people living with dementia, and other stakeholders, in achieving dementia friendly care. These include education and awareness raising initiatives, facilitating groups designed to promote and engage people living with dementia in meaningful activities that enable social citizenship to be enacted; as well as ways professionals have approached the challenge of attaining shared decision making. Tools offer a way to both measure successful outcomes, and also a mechanism for professionals to seek to engage and involve stakeholders. If such methods are developed further, then we will likely be one step closer to achieving the aim of dementia friendly care outcomes that are underpinned by social citizenship and social inclusion principles.

Disclosure

The authors report no conflicts of interest in this work.

References

1. World Health Organization. The global network for age-friendly cities and communities. looking back over the last decade, looking forward to the next; 2018. Available from: <http://apps.who.int/bookorders>. Accessed August 5, 2021.
2. Prince M, Wimo A, Guerchet M, Ali G, Wu Y, Prina M. World alzheimer report 2015 the global impact of dementia. *alzheimer's disease international* [Internet]; 2015. Available from: <https://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf>. Accessed August 5, 2021.
3. Department of Health. Prime Minister's challenge on dementia [Internet]. London; 2012. Available from: <http://dementia.dh.gov.uk/prime-ministers-challenge-on-dementia-improvements-to-health-and-care/>. Accessed August 5, 2021.
4. Department of Health. Prime Minister's challenge on dementia 2020 [Internet]. London; 2015. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf. Accessed August 5, 2021.
5. Alzheimer's Society. *Dementia 2014: Opportunity for Change*. Alzheimer's Society; 2014.

6. Alzheimer's Disease International. Dementia Friendly Communities Global developments [Internet]. London; 2017. Available from: <https://www.alzint.org/u/dfc-developments.pdf>. Accessed August 5, 2021.
7. Lin SY. "Dementia-friendly communities" and being dementia friendly in healthcare settings. *Curr Opin Psychiatry*. 2017;30(2):145–150. doi:10.1097/YCO.0000000000000304
8. Hebert CA, Scales K. Dementia friendly initiatives: a state of the science review. *Dementia*. 2019;18(5):1858–1895. doi:10.1177/1471301217731433
9. Lin SY, Lewis FM. Dementia friendly, dementia capable, and dementia positive: concepts to prepare for the future. *Gerontologist*. 2015;55(2):237–244. doi:10.1093/geront/gnu122
10. Alzheimer's Disease International and World Health Organisation. A public health priority [Internet]. UK; 2012. Available from: http://apps.who.int/iris/bitstream/handle/10665/75263/9789241564458_eng.pdf;jsessionid=6E0CF395F146E47D727BA5582C977E4A?sequence=1. Accessed August 5, 2021.
11. Wied TS, Knebel M, Tesky VA, Haberstroh J. The human right to make one's own choices - implications for supported decision-making in persons with dementia: a systematic review. *Eur Psychol*. 2019;24(2):146–158.
12. Geddis-Regan A, Errington L, Abley C, Wassall R, Exley C, Thomson R. Enhancing shared and surrogate decision making for people living with dementia: a systematic review of the effectiveness of interventions. *Heal Expect*. 2021;24(1):19–32.
13. Perach R, Rusted J, Harris PR, Miles E. Emotion regulation and decision-making in persons with dementia: a scoping review. *Dementia*. 2020;1(5):1–23.
14. Birt L, Griffiths R, Charlesworth G, et al. Maintaining social connections in dementia: a qualitative synthesis. *Qual Health Res*. 2020;30(1):23–42. doi:10.1177/1049732319874782
15. Bazooband A, Courtney-Pratt H, Doherty K. Participatory community-based arts for older people living with dementia in the community: how are they evaluated? A scoping review. *Geriatr Care*. 2021;7(1). doi:10.4081/gc.2021.9470
16. Bellas S, Balmer A, May V, et al. Broadening the debate on creativity and dementia: a critical approach. *Dementia*. 2018;2:147130121876090.
17. Bartlett R, Connor DO. From personhood to citizenship: broadening the lens for dementia practice and research. *J Aging Stud*. 2007;21:107–118. doi:10.1016/j.jaging.2006.09.002
18. Baldwin C, Greason M. Micro-citizenship, dementia and long-term care. *Dementia*. 2016;15(3):289–303. doi:10.1177/1471301216638762
19. Bethell J, Pringle D, Chambers LW, et al. Patient and public involvement in identifying dementia research priorities. *J Am Geriatr Soc*. 2018;66(8):1608–1612. doi:10.1111/jgs.15453
20. Poland F, Charlesworth G, Leung P, Birt L. Embedding patient and public involvement: managing tacit and explicit expectations. *Heal Expect*. 2019;22(6):1231–1239. doi:10.1111/hex.12952
21. Walsh M, Griffiths AW. Navigating meaningful involvement: do the 'core principles for involving people with dementia in research' offer a useful framework? *Dementia*. 2020;19(1):101–106. doi:10.1177/1471301219876714
22. Stevenson M, Taylor BJ. Involving individuals with dementia as co-researchers in analysis of findings from a qualitative study. *Dement Int J Soc Res*. 2019;18(2):701–712. doi:10.1177/1471301217690904
23. Gove D, Diaz-Ponce A, Georges J, et al. Alzheimer Europe's position on involving people with dementia in research through PPI (patient and public involvement). *Aging Ment Heal*. 2018;22(6):723–729. doi:10.1080/13607863.2017.1317334
24. Page MJ, McKenzie JE, Bossuyt PM, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ*. 2021;372:2020–2021.
25. Dupuis SL, Kontos P, Mitchell G, Jonas-Simpson C, Gray J. Reclaiming citizenship through the arts. *Dementia*. 2016;15(3):358–380. doi:10.1177/1471301216637206
26. Mann J. Canadian charter of rights for people with dementia. *Dementia*. 2020;19(1):63–67. doi:10.1177/1471301219876503
27. Phinney A, Kelson E, Baumbusch J, O'Connor D, Purves B. Walking in the neighbourhood: performing social citizenship in dementia. *Dementia*. 2016;15(3):381–394. doi:10.1177/1471301216638180
28. Theurer K, Wister A, Sixsmith A, Chaudhury H, Lovegreen L. The development and evaluation of mutual support groups in long-term care Homes. *J Appl Gerontol*. 2014;33(4):387–415. doi:10.1177/0733464812446866
29. Wiersma EC, O'Connor D, Loiselle L, et al. Creating space for citizenship: the impact of group structure on validating the voices of people with dementia. *Dementia*. 2016;15(3):414–433. doi:10.1177/1471301216642339
30. Goeman DP, Corlis M, Swaffer K, et al. Partnering with people with dementia and their care partners, aged care service experts, policy-makers and academics: a co-design process. *Australas J Ageing*. 2019;38(S2):53–58. doi:10.1111/ajag.12635
31. Donnelly S, Begley E, O'Brien M. How are people with dementia involved in care-planning and decision-making? An Irish social work perspective. *Dementia*. 2019;18(7–8):2985–3003. doi:10.1177/1471301218763180
32. Morgan-Brown M, Brangan J, McMahon R, Murphy B. Engagement and social interaction in dementia care settings. A call for occupational and social justice. *Heal Soc Care Community*. 2019;27(2):400–408. doi:10.1111/hsc.12658
33. Groen-van De Ven L, Smits C, De Graaff F, et al. Involvement of people with dementia in making decisions about their lives: a qualitative study that appraises shared decision-making concerning daycare. *BMJ Open*. 2017;7(11):1–13. doi:10.1136/bmjopen-2017-018337
34. Österholm JH, Hydén LC. Citizenship as practice: handling communication problems in encounters between persons with dementia and social workers. *Dementia*. 2016;15(6):1457–1473. doi:10.1177/1471301214563959
35. Mayrhofer AM, Mathie E, McKeown J, Goodman C, Irvine L, Natalie Hall MW. Young onset dementia: public involvement in co-designing community-based support. *Aging Ment Health*. 2017;22(8):933–941. doi:10.1080/13607863.2017.1334038
36. Waller S, Masterson A, Evans SC. The development of environmental assessment tools to support the creation of dementia friendly care environments: innovative practice. *Dementia*. 2017;16(2):226–232. doi:10.1177/1471301216635829
37. Grace S, Horstmanshof L. A realist evaluation of a regional dementia health literacy project. *Heal Expect*. 2019;22(3):426–434. doi:10.1111/hex.12862
38. Buckner S, Darlington N, Woodward M, et al. Dementia friendly communities in England: a scoping study. *Int J Geriatr Psychiatry*. 2019;34(8):1235–1243. doi:10.1002/gps.5123
39. Wu SM, Huang HL, Chiu YC, et al. Dementia-friendly community indicators from the perspectives of people living with dementia and dementia-family caregivers. *J Adv Nurs*. 2019;75(11):2878–2889. doi:10.1111/jan.14123
40. Guest MA, Smith MP. In our community, dementia speaks: pilot of a person-centered training targeting African-American caregivers of persons-living with dementia (innovative practice). *Dementia*. 2021;20(1):391–397. doi:10.1177/1471301219885784

41. Parke B, Boltz M, Hunter KF, et al. A Scoping literature review of dementia-friendly hospital design. *Gerontologist*. 2017;57(4):e62–74.
42. Bennett CE, De Boos D, Moghaddam NG. Developing a tool to support diagnostic delivery of dementia. *Dementia*. 2019;18(7–8):2505–2525. doi:10.1177/1471301217750936
43. Egdell V, Cook M, Stavert J, Ritchie L, Tolson D, Danson M. Dementia in the workplace: are employers supporting employees living with dementia? *Aging Ment Heal*. 2021;25(1):134–141. doi:10.1080/13607863.2019.1667299

Journal of Healthcare Leadership

Dovepress

Publish your work in this journal

The Journal of Healthcare Leadership is an international, peer-reviewed, open access journal focusing on leadership for the health profession. The journal is committed to the rapid publication of research focusing on but not limited to: Healthcare policy and law; Theoretical and practical aspects healthcare delivery; Interactions between healthcare and society and evidence-based practices; Interdisciplinary decision-making;

Philosophical and ethical issues; Hazard management; Research and opinion for health leadership; Leadership assessment. The manuscript management system is completely online and includes a very quick and fair peer-review system. Visit <http://www.dovepress.com/testimonials.php> to read real quotes from published authors.

Submit your manuscript here: <https://www.dovepress.com/journal-of-healthcare-leadership-journal>