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Creating dementia-friendly community for social inclusion: a scoping review protocol

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4 **Title: Creating dementia-friendly community for social inclusion: a scoping review protocol**
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42 **Abstract**

43 **Introduction:** The number of people with dementia is increasing across countries with the majority of
44 people with dementia living at home in the community. The World Health Organization calls for global
45 action on the public health response to dementia. Social exclusion is commonly reported by people living
46 with dementia and their families. Dementia-friendly community has emerged as an idea that holds
47 potential to contribute to mitigation of social exclusion. For developing better models of dementia-friendly
48 communities, there is a need to identify strategies, impact, and lessons learned in the literature.
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50 **Methods and Analysis:** This scoping review will follow Joanna Briggs Institute scoping review
51 methodology. The proposed review will consider studies based in community settings with participants
52 living at home with early to late stages of dementia and their families. This includes a three-step search
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strategy: (1) to identify keywords from CINAHL & AgeLine; (2) to conduct a second search using all identified keywords and index terms across select databases; and (3) to hand search the reference lists of all included articles and reports for additional studies. In addition, we will search Google for grey literature on published organizational reports. Three researchers will screen titles and abstracts independently; then assess full text of selected citations against inclusion criteria. Extracted data will be presented in a narrative accompanied by tables that reflect the objective of the review.

Ethics and dissemination: This scoping review provides an overview of current evidence on strategies that support dementia-friendly communities for social inclusion. The findings will offer insights to inform strategies for education, practice, policy and future research. We will share the scoping review results through conference presentations and an open access publication in a peer-reviewed journal.

Keywords: dementia friendly community, dementia, social inclusion, scoping

Strengths and Limitations

- People with lived experiences, families of people with dementia, health organizational leaders, and community representatives will be involved in conducting and disseminating the scoping review.
- This is a novel and timely topic to understand how dementia-friendly community may support social inclusion among people with dementia living in community home settings.
- The results and recommendations of scoping reviews cannot be graded as no methodological appraisal of the quality of included studies will take place.
- Studies published in non-English will be missed.
- Strategies for building dementia friendliness in hospitals and other formal healthcare settings will not be captured.

Introduction

The number of people living with dementia is growing exponentially across countries. Worldwide, around 50 million people live with dementia; there are nearly 10 million new cases every year. [1] People living with dementia and their family/friend care providers face challenges including; stigma, social exclusion, difficulty accessing formal and informal support and financial pressures. The World Health Organization declared dementia as a public health priority. The global action plan calls for actions to address dementia as a public health priority, increase awareness of dementia, establish dementia-friendly initiatives, support for dementia carers, and research and innovation. The current efforts of promoting dementia-friendly communities have potential to promote social inclusion, change attitudes and behaviours, and to support people with dementia to be engaged in communities in meaningful ways.

In a recent UK report, people with dementia reported that they don't know how to contribute to their local community, and they have an overriding sense of low expectations and low self-belief. [2] The development of dementia-friendly community has potential to empower people with dementia to feel confident, knowing they can contribute and participate in activities that are meaningful to them. [3] In Australia, people with dementia identified six priorities in creating dementia-friendly communities: increased awareness and understanding of dementia; access to social activities; support to stay at home; appropriate health care; transport; and improvements to the physical environment.[4] In Canada, the notion of social inclusion has been underlined as essential for people with dementia. [5] The impact of both supportive physical and social environments have been identified as vital to social inclusion, empowerment, and enablement for people living with dementia to contribute to and participate in society.[6,7] Active involvement of people with dementia and their families is also considered as a key enabler in the development of dementia-friendly community. [8] "Nothing about us without us" is a phrase which has been frequently expressed by people with dementia in public campaign. [9]

In June 2019, the Government of Canada released the national dementia strategy. 'Promoting social inclusion and dementia-inclusive communities' was one of the areas of focus in the Canadian dementia strategy.[10] The Public Health Agency of Canada launched the Dementia Community Investment, a four million dollar per year ongoing investment, which funds community-based projects that seek to optimize the wellbeing of people living with dementia and/or the family members and friends who care for them by; increase knowledge of dementia and its risk factors; undertake intervention research to assess the effectiveness of the program or initiative and apply that knowledge to support expansion of the project's reach to new communities, sectors, and populations.[11] However, knowledge about strategies that enable effective development of dementia-friendly communities remains limited and there is a need to identify gaps, evidence, and enabling approaches to inform education, practice, policy and future research.

Dementia-friendly community

Dementia-friendly community can be defined as a city, town or village where people with dementia are understood, respected and supported. [12] The notion of dementia-friendly community has drawn from Age-Friendly Cities initiative of the World Health Organization. [11] Age-friendly communities involves bringing stakeholders together to help create more inclusive environments in local communities to promote active and healthy aging. [13] Age-friendly communities contribute to good health and allow people to continue to participate fully in society.[12] A similar guiding principle that dementia friendly and age friendly approaches both embody is - empowering local stakeholders to collaborate and contribute for social inclusion. Public education, reduction of stigma, and removing barriers in physical and social environments are common themes in dementia-friendly initiatives as well. [14] Dementia advocates, Rahman and Swaffer criticized the term 'dementia-friendly', is still deficit-focused, indicating a sense of otherness with an illness model, and thus they argued for assets-based approaches. [15]

Social inclusion

Social inclusion in this review refers to a dynamic process where people engage with, and are part of, their social networks in the community to maintain meaningful social relations. Social connection and a sense of belonging are essential to well-being and quality of life. [5] Purposeful-connection, doing meaningful activities together, are important to a person with dementia and their families/care providers.[16,17] While people with dementia can benefit from their local community network; social inclusion and social participation promote a sense of social citizenship, safety and contribution. [18] The existing literature suggests there is potential for dementia-friendly community to support social inclusion. Stigma is one of the key challenges that people with dementia face. Stigma and lack of understanding cause people in societies to behave in ways that focus on problems of the disease rather than supporting the abilities that people with dementia have.[9] Considering stigma and social exclusion are important issues for people with dementia living in communities, interventions that engage and include people living with dementia in community activities seem vital to help people with dementia to live their best life at home.

A preliminary search of CINAHL, PubMed, PsycINFO, and the JBI Database of Systematic Reviews and Implementation Reports conducted on Sept 30, 2019 found no systematic review examining strategies that support dementia-friendly communities for social inclusion in the community home settings.

In an integrative review, Shannon et al (2018) found eight papers that described the characteristics of dementia-friendly communities, as well as barriers and enablers to community engagement for people living with dementia. [8] Five of those papers were reports in the grey literature and three were research study articles. Our scoping review will expand on the contributions of work Shannon et al (2018) by capturing a diverse range of evidence in a wider search. We will include search in Google and ProQuest to find organizational reports and thesis published by universities. As stated by Bartlett, the notion of a

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3 'dementia friendly community' is in its infancy and undertheorized, so the challenges of realizing it have
4 yet to be fully scoped or invoked" (p. 456). There is a need to categorize the current research regarding
5 helpful strategies that enable dementia-friendly communities to inform education, practice, policy and any
6 need of further research. When a research topic is new and its meaning has not been fully established,
7 scoping reviews are useful to systematically map and synthesize the current state of knowledge.[19]
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11 The main objective of the scoping review is to systematically chart the body of literature on
12 strategies/approaches utilized for creating dementia-friendly communities that support people with
13 dementia and their informal care providers. The review study will clarify the key concepts/definitions
14 related to dementia friendly communities and report the types of intervention implemented to promote
15 social inclusion.
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19 20 **Review question**

21 What has been reported in the literature about strategy for developing dementia friendly community that
22 supports social inclusion?
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25 26 **Inclusion criteria**

27 **Participants**

28 This review will consider studies as well as grey literature that include young and older persons living at
29 home in the communities. Studies that focus on neighbors, local citizens, public and private service
30 providers, care providers and families of people with dementia in the community that promote dementia
31 friendly community will also be included. We do not limit the participant's age as evidence of identifies
32 young onset of, <65.
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36 37 **Concept**

38 This scoping review aims to identify strategies for dementia friendly community that supports social
39 inclusion. Relevant concepts include any type of intervention or approaches that enable social inclusion,
40 social participation, social citizenship, quality of life, wellbeing, and empowerment.
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44 45 **Context**

46 Community in this review refers to people residing at home in a local geographical area. Studies in
47 targeted formal healthcare organizations such as long-term care facilities and hospitals will be not
48 considered in this review.
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51 52 **Types of studies**

53 This scoping review will consider studies published in English with no time limit. A wide range of study
54 designs from controlled trials to descriptive studies will be considered. As well as, small pilot study, case
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3 reports and observational studies will be considered for inclusion. This review will also consider student
4 thesis published by universities.
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6 7 **Methods**

8 The proposed systematic review will be conducted in accordance with the Joanna Briggs Institute
9 methodology for scoping reviews.[19]
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13 **Search strategy**

14 The search strategy aims to locate both published and unpublished literature, including theses and
15 dissertations. A three-step search strategy will be used. An initial limited search of CINAHL and Ageline,
16 will be conducted using the selected keywords. The initial search will be followed by analysis of the text
17 words contained in the titles and abstracts of relevant articles, as well as the index terms used to describe
18 these articles. A second search, using all identified keywords and index terms, will then be undertaken
19 and adapted for each included information source. Lastly, the reference lists of all included articles and
20 reports will be screened for additional studies. A full search strategy for CINAHL is included in
21 supplementary file 1.
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27 **Information sources**

28 The databases to be searched include CINAHL, Ageline, MEDLINE, PsycINFO, Web of Science and
29 ProQuest. The search for unpublished studies and grey literature will include: Agency for Healthcare
30 Research and Quality (AHRQ), Centres for Health Evidence, Google Scholar, ProQuest Dissertations and
31 Theses Databases, Public Health Agency of Canada and TRIP (Turning Research into Practice). Google
32 will be searched as well by using phrases search. For example: “dementia friendly community” and “social
33 inclusion”.
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39 **Study selection**

40 Following the search, all identified citations will be collated and uploaded into Mendeley and duplicates
41 removed. Titles and abstracts will then be screened by three independent researchers (the first three
42 authors) for assessment against the inclusion criteria for the review. Potentially relevant studies will be
43 retrieved in full and their citation details imported into the Joanna Briggs Institute System for the Unified
44 Management, Assessment and Review of Information (JBI SUMARI) (Joanna Briggs Institute, Adelaide,
45 Australia). The full text of selected citations will be assessed in detail against the inclusion criteria by
46 three independent researchers. Reasons for exclusion of full text studies that do not meet the inclusion
47 criteria will be recorded and reported in the systematic review. Any disagreements that arise between the
48 reviewers at each stage of the study selection process will be resolved through discussion, with the fourth
49 author. The results of the search will be reported in full in the final report and presented in a Preferred
50 Reporting Items for Systematic Reviews and Meta-analyses (PRISMA-ScR) flow diagram.
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Data extraction

Data will be extracted from papers included in the scoping review by three independent researchers using a data extraction tool. The data extracted will include specific details about the population, concept, context, study methods and key findings relevant to the review objective. A draft charting table is provided (see supplementary file 2). The data extraction tool will be pilot tested having all researchers' complete extraction from three data sources and comparing results. The draft data extraction tool will be modified and revised as necessary during the process of extracting data from each included study. Modifications will be detailed in the full scoping review report. Any disagreements that arise between the reviewers will be resolved through discussion, or with a fourth reviewer. Authors of identified or included papers will be contacted to request missing or additional data, where required.

Ethics and Dissemination

Research ethics approval and consent to participate is not required for this scoping review. The extracted data and results will be presented in tabular table to summarize and map the existing literature. A narrative summary will accompany the charted results to describe the characteristics of the literature on dementia friendly community strategies that supports social inclusion. Barriers that hinder the development and practical lessons will also be identified. The categories that will be used for data presentation include, year of publication, country, context, population, intervention types, enabling strategies and impacts related to dementia-friendly communities that support social inclusion. The authors anticipate the findings will be a critical step to provide evidence-based guidance to inform future practice, policy and research. The results will be disseminated at regional, national, and international conferences. The findings will be made accessible to health professionals, policy and decision makers, and the public.

Patient and public involvement

Two patient partners (persons with early stage of dementia) and two family partners (persons who have a family member with dementia) will be engaged in regular monthly research meetings to discuss data extracted and validate study results. Patient and family partners were recruited from a local community organization, the Community Engagement Advisory Network (CEAN). More information about how CEAN supports patient and public involvement can be found in <http://cean.vch.ca>. Also, we will invite organizational leaders in local health authorities and representatives of local Alzheimer Society to engage in a workshop day for discussion and seek input and feedback on the results and contribute to dissemination through the organizational website and in-person meetings/ conferences.

Contributors LH conceived the idea, developed the research protocol and methods and drafted and edited the final manuscript. SL, RH, AP helped to refine and develop the research question and study methods and made meaningful contributions to the drafting and editing of the manuscript. All authors approved the final manuscript submitted.

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Competing interests None declared.

Patient consent Not required.

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Supplementary file 1: Search strategy for CINAHL

#	Searches	Results
S1	("community") OR ("city") OR ("neighborhood") OR ("environment")	150,564
S2	(MH Dementia* OR Alzheimer) MH= CINAHL exact subject headings	69,178
S3	(social* N3 (isolate* OR connect* OR engage* OR integrate* OR interact*)) OR wellbeing OR "well being"	73,173
S4	(MH "Exclusion") OR (MH "Social Isolation*") OR (MH "Social Participation") OR (MH "Social Inclusion") OR (MH "Quality of Life*") OR (MH "Psychosocial") OR (MH "Stigma")	13,431
S5	(Dementia-friendliness*) OR (Dementia-capable*) OR (Age-friendly*)	281
S6	S1 OR S2	474, 250
S7	S3 OR S4	85,664
S8	S5 AND S6 AND S7	42

Supplementary file 2: Data extraction tool

Author, Year & country	Context or Setting	Population or Participants	Type of Article	Strategies	Outcome and Impact	Barriers and lessons learned

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Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	P.1 title
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	P.1-2 Abstract and article summary
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	P.3 Introduction
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	P. 5 Study objective, population, concepts, and context, review question
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	This article is the protocol for the scoping review
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	P. 5 inclusion criteria
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	P. 6 Searches and study selection, Supplementary file 1, a sample of literature search with Boolean operators and truncation
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Supplementary file 1
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	P. 6 Study selection
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any	P.7 Data extraction and charting process, supplementary file 2 – data extraction instrument



SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
		processes for obtaining and confirming data from investigators.	
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	P. 5
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	NA. Quality appraisal will not be performed on studies in this scoping review.
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	To be conducted in the scoping review
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	To be conducted in the scoping review
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	To be conducted in the scoping review
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	NA
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	To be conducted in the scoping review
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	To be conducted in the scoping review
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	To be conducted in the scoping review
Limitations	20	Discuss the limitations of the scoping review process.	P.2
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	To be conducted in the scoping review
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	P.7

JB1 = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.



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3 † A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g.,
4 quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping
5 review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).
6 ‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the
7 process of data extraction in a scoping review as data charting.
8 § The process of systematically examining research evidence to assess its validity, results, and relevance before
9 using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable
10 to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used
11 in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).
12

13
14 *From:* Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-
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Secondary Subject Heading:	Mental health, Evidence based practice
Keywords:	Dementia < NEUROLOGY, International health services < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, SOCIAL MEDICINE

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4 **Title: Creating dementia-friendly communities for social inclusion: a scoping review protocol**
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33 Authors declare no conflicts of interest
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36 Word count: 2075
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42 **Abstract**

43 **Introduction:** The number of people with dementia is increasing worldwide, with the majority of people
44 with dementia living at home in the community. The World Health Organization calls for global action on
45 the public health response to dementia. Social exclusion is commonly reported by people with dementia
46 and their families. Dementia-friendly community has emerged as an idea that holds potential to contribute
47 to the mitigation of social exclusion. The objective of the scoping review is to identify strategies and
48 impact of creating dementia-friendly communities that support people with dementia and their informal
49 care providers.
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Methods and Analysis: This scoping review will follow the Joanna Briggs Institute scoping review methodology and will take place between February and June 2020. The proposed review will consider studies based in community settings with participants living at home with early to late stages of dementia and their families. This includes a three-step search strategy: (1) to identify keywords from CINAHL & AgeLine; (2) to conduct a second search using all identified keywords and index terms across selected databases (CINAHL, AgeLine, MEDLINE, PsycINFO, Web of Science, ProQuest and Google); and (3) to hand-search the reference lists of all included articles and reports for additional studies. Further, we will search Google for grey literature on published organizational reports. Three researchers will screen titles and abstracts independently and then assess the full text of selected citations against inclusion criteria. Extracted data will be presented in a narrative accompanied by tables that reflect the objective of the review.

Ethics and Dissemination: This scoping review provides an overview of current evidence on strategies that support dementia-friendly communities for social inclusion. The findings will offer insights to inform strategies for education, practice, policy and future research. We will share the scoping review results through conference presentations and an open-access publication in a peer-reviewed journal.

Keywords: dementia-friendly community, dementia-inclusive community, dementia, social inclusion, scoping

Strengths and Limitations:

- People with lived experience, families of people with dementia, leaders of health organizations, and community representatives will be involved in conducting and disseminating the scoping review.
- This is a novel and timely topic to understand how dementia-friendly community may support social inclusion among people with dementia living at home in the community.
- The results and recommendations of scoping reviews cannot be graded since methodological appraisal of the quality of included studies is not consistent with the Joanna Briggs Institute scoping review guidelines.
- Studies not published in English will be missed.
- Strategies for building dementia friendliness in hospitals and other formal healthcare settings will not be captured.

INTRODUCTION

The number of people with dementia is growing exponentially across the world. Globally, around 50 million people live with dementia; there are nearly 10 million new cases every year. [1] People with dementia and their informal caregivers face challenges that include stigma, social exclusion, difficulty accessing formal and informal support resources and financial pressures. The World Health Organization has declared dementia as a public health priority. [1] The global action plan calls for actions to address dementia as a public health priority, increase awareness of dementia, establish dementia-friendly initiatives, provide support for dementia carers, and conduct research and innovation. Social exclusion and isolation can have detrimental effects on mental and physical health, such as depression and cardiovascular health. [2] Current efforts to promote dementia-friendly communities have the potential to promote social inclusion, change attitudes and behaviours, and support people with dementia to be engaged in community in meaningful ways.

Dementia-Friendly Community and Social Inclusion

A dementia-friendly community can be defined as a city, town or village where people with dementia are understood, respected and supported. [3] Social inclusion refers to a dynamic process where people engage with, and are part of, their social networks in the community to maintain meaningful social relations. [4] Social connection and a sense of belonging are essential to well-being and quality of life. [4] Purposeful connection, doing meaningful activities together, are important to a person with dementia and their families/care providers.[5,6] People with dementia can benefit from their local community network; social inclusion and social participation promote a sense of social citizenship, safety and contribution. [7] The existing literature suggests there is potential for dementia-friendly community to support social inclusion. Stigma is one of the key challenges that people with dementia face. Stigma and lack of understanding cause people in societies to behave in ways that focus on problems of the disease rather than supporting the abilities that people with dementia have.[8] Considering stigma and social exclusion are important issues for people with dementia living in the community, interventions that engage and include people with dementia in community activities seem vital to help people with dementia to live their best life at home.

The notion of dementia-friendly community has been drawn from the Age-Friendly Cities initiative of the World Health Organization. [9] Age-friendly communities involves bringing stakeholders together to help create more inclusive environments in local communities in order to promote active and healthy aging. [10] Age-friendly communities contribute to good health and allow people to continue to participate fully in society.[3] A similar guiding principle that dementia-friendly and age-friendly strategies both embody is - empowering local stakeholders to collaborate and contribute for social inclusion. Public education, reduction of stigma, and removal of barriers in physical and social environments are common themes in

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3 dementia-friendly initiatives as well. [11] Dementia advocates Rahman and Swaffer have criticized the
4 term 'dementia-friendly' for its implied focus on deficit, suggesting a sense of otherness identified with an
5 illness model, and thus they argue for an assets-based focus. [12] We acknowledge the need to shift the
6 attention to strengths and assets that people with dementia can bring. We chose to use the term
7 'dementia-friendly' for the scoping review for two reasons: first, 'dementia-friendly' is the most common
8 term used in the literature and government initiatives; second, as suggested by Lin and Lewis (2015),
9 'dementia-friendly' has a focus on lived experience and inclusive environments, which have an important
10 influence on inclusion and acceptance. [13]
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16 In the UK, dementia-friendly communities were found in regions with a large population of people living
17 with dementia. [14] Yet, people with dementia reported that they didn't know how to contribute to their
18 local community, and that they had an overriding sense of low expectation and low self-belief. [15] As the
19 development of dementia-friendly community has the potential to empower people with dementia, it is
20 important to better understand what makes dementia-friendly communities effective. [16,17] In Australia,
21 people with dementia identified six priorities in creating dementia-friendly communities: increased public
22 awareness and understanding of dementia, access to social activities, support to stay at home,
23 appropriate health care, transport; and improvements to the physical environment.[18] Stigma was
24 viewed as a key barrier to community engagement, thereby leading to social isolation among people with
25 dementia. [19] In Canada, the notion of social inclusion has been underlined as essential for people with
26 dementia. [4] The impact of both supportive physical and social environments has been identified as vital
27 to social inclusion, empowerment, and enablement for people with dementia to contribute to and
28 participate in society.[20,21] Active involvement of people with dementia and their families is also
29 considered to be a key enabler in the development of dementia-friendly community. [22] "Nothing about
30 us without us" is a phrase borrowed from the disability movement which has been frequently expressed
31 by people with dementia in public campaigns. [8]
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40 To date, knowledge about strategies that promote effective development of dementia-friendly
41 communities remains limited, indicating that there is a need to identify enabling strategies to inform
42 education, practice, policy and future research.[23] In this scoping review study, 'strategy' refers to an
43 action plan and interventions conducted to achieve the goal of creating dementia-friendly communities. In
44 June 2019, the Government of Canada released its national dementia strategy. 'Promoting social
45 inclusion and dementia-inclusive communities' was one of the areas of focus in the Canadian dementia
46 strategy.[24] The Public Health Agency of Canada launched the Dementia Community Investment, a four
47 million dollar per year ongoing investment, which funds community-based projects that seek to achieve
48 the following: optimize the wellbeing of people with dementia and their informal caregivers; increase
49 public knowledge of dementia and its risk factors; undertake intervention research to assess the
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effectiveness of the program or initiative; and apply that knowledge to support expansion of the project's reach to new communities, sectors, and populations.[9]

A preliminary search of CINAHL, PubMed, PsycINFO, and the Joanna Briggs Institute (JBI) Database of Systematic Reviews and Implementation Reports conducted on Sept 30, 2019 found no systematic review examining strategies that support dementia-friendly communities for social inclusion in the community home settings.

In an integrative review, Shannon et al (2018) found eight papers that described the characteristics of dementia-friendly communities, as well as barriers and enablers to community engagement for people with dementia. [22] Five of those papers were reports in the grey literature and three were research study articles. Our scoping review will expand on the contributions by Shannon et al (2018) by capturing a diverse range of evidence in a wider search. We will include searches in Google and ProQuest to find organizational reports and theses published by universities. This scoping review will map the accessible literature to provide an overview of current evidence regarding helpful strategies that enable dementia-friendly communities to inform education, practice, policy and further research. As pointed out by the Joanna Briggs Institute, when a research topic is new and its meaning has not been fully established, scoping reviews are useful to systematically map and synthesize the current state of knowledge.[25]

The main objective of the scoping review is to chart the body of literature on strategies and impacts of creating dementia-friendly communities that support people with dementia and their informal care providers.

Review Question

What has been reported in the literature regarding strategies for developing dementia-friendly communities that support the impact of social inclusion?

Inclusion Criteria

Participants

This review will include young and older people with dementia living at home in the community. Studies that focus on neighbours, local citizens, public and private service providers, care providers and families of people with dementia in the community that promote dementia-friendly community will also be included.

Concept

This scoping review aims to identify strategies for dementia-friendly communities that support social inclusion. The core concept is strategy. Such strategies may include activities that change attitudes and

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3 behaviours to reduce stigma and social exclusion in a community or any interventions that create positive
4 impact such as social inclusion and social participation of people with dementia. For example, any articles
5 that report on public awareness initiatives, education and training about dementia, development of
6 physical environment guidelines will be considered. 'Impact' refers to a broad range of changes that occur
7 as a result of dementia-friendly community strategy. Improved public knowledge of dementia and
8 increased social participation of people with dementia are examples of positive impact of social inclusion.
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12 **Context**

13 Community in this review refers to people residing at home in a local geographical area. Studies in
14 targeted formal healthcare organizations such as long-term care facilities and hospitals will be not
15 considered in this review.
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19 **Types of Studies**

20 This scoping review will consider studies published in English with no time limit. A wide range of study
21 designs from randomized controlled trials to descriptive studies will be considered. Small pilot studies,
22 case reports, observational studies, quantitative and qualitative studies and all other studies will be
23 considered for inclusion. This review will also consider student theses published by universities.
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28 **METHODS**

29 The proposed scoping review will be conducted in accordance with the Joanna Briggs Institute
30 methodology for scoping reviews.[25] This scoping study will take place between February and June
31 2020.
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36 **Search Strategy**

37 The search strategy aims to locate both published and unpublished literature, including theses and
38 dissertations. A three-step search strategy will be used. An initial limited search of CINAHL and AgeLine
39 will be conducted using the selected keywords. The initial search will be followed by analysis of the text
40 words contained in the titles and abstracts of relevant articles, as well as the index terms used to describe
41 these articles. A second search, using all identified keywords and index terms, will then be undertaken
42 and adapted for each included information source. Lastly, the reference lists of all included articles and
43 reports will be screened for additional studies. A full search strategy for CINAHL is included in
44 supplementary file 1.
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50 **Information Sources**

51 The databases to be searched include CINAHL, Ageline, MEDLINE, PsycINFO, Web of Science and
52 ProQuest. Google will be searched as well by using phrases such as "dementia friendly community" and
53 "social inclusion".
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Study Selection

Following the search, all identified citations will be collated and uploaded into Mendeley and duplicates removed. Titles and abstracts will then be screened by two independent researchers (LH and SL) for assessment against the inclusion criteria for the review. Potentially relevant studies will be retrieved in full, and their citation details imported into the Joanna Briggs Institute System for the Unified Management, Assessment and Review of Information (JBI SUMARI) (Joanna Briggs Institute, Adelaide, Australia). The full text of selected citations will be assessed in detail against the inclusion criteria by two independent researchers. Reasons for exclusion of full-text studies that do not meet the inclusion criteria will be recorded and reported in the systematic review. Any disagreements that arise among the reviewers at each stage of the study selection process will be resolved through discussion. If consensus cannot be achieved, the senior scientist (AP) will facilitate discussion to foster the decision-making process. The results of the search will be reported in full in the final report and presented in a Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA-ScR) flow diagram.

Data Extraction

Data will be extracted from papers included in the scoping review by two researchers using a data extraction tool. The data extracted will include specific details about the population, concept, context, study methods and key findings relevant to the review objective. A draft charting table is provided (see supplementary file 2). The data extraction tool will be pilot-tested; two independent researchers will complete extraction from three studies and compare results. The draft data extraction tool will be modified and revised as necessary during the process of extracting data from each included study. Modifications will be detailed in the full scoping review report. Any disagreements that arise between the reviewers will be resolved through discussion. If consensus cannot be reached, the senior scientist AP will be consulted.

Patient and Public Involvement

Two patient partners (people with early stage of dementia) and two family partners (people who have a family member with dementia) will be engaged in regular monthly research meetings to discuss extracted data and validate study results. Patient and family partners were recruited from a local community organization, the Community Engagement Advisory Network (CEAN). More information about how CEAN supports patient and public involvement can be found at <http://cean.vch.ca>. Also, we will invite organizational leaders in local health authorities and representatives of local Alzheimer Society chapters to engage in a day-long workshop. The aim of the workshop is to discuss input and seek feedback on the scoping review results, with the goal of having these workshop participants disseminate the results on their respective organizational websites and in-person meetings and conferences.

Ethics and Dissemination

Research ethics approval and consent to participate is not required for this scoping review. The results will be disseminated at regional, national, and international conferences. The findings will be made accessible to health professionals, policy and decision makers, and the public.

Data Synthesis

The extracted data and results will be presented in table to summarize and map the existing literature. A narrative summary will accompany the tabled results to describe the characteristics of the literature on dementia-friendly community strategies that support social inclusion. The categories that will be used for data presentation include: year of publication, country, context, population, intervention types, enabling strategies and impacts related to dementia-friendly communities that support social inclusion. The authors anticipate the findings will be a critical step in providing evidence-based guidance to inform future practice, policy and research.

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Contributors LH conceived the idea, developed the research protocol and methods, and drafted and edited the final manuscript. SL, RH, AP helped to refine and develop the research question and study methods and made meaningful contributions to the drafting and editing of the manuscript. All authors approved the final manuscript submitted.

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Competing interests None declared.

Patient consent Not required.

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Supplementary file 1: Search strategy for CINAHL

#	Searches	Results
S1	dement* or alzheimer*	82,877
S2	(community or communities) OR (city or cities) OR (neighborhood or neighborhoods) OR (environment or environments)	463,213
S3	friendly or friendliness or capable or inclusive	21,844
S4	S1 AND S2 AND S3	206

For peer review only

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Supplementary file 2: Data extraction tool

Author, Year & country	Context or Setting	Population or Participants	Type of Article	Study design	Strategies	Impact

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Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	P.1 title
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	P.1-2 Abstract and article summary
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	P.3 Introduction
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	P. 5 Study objective, population, concepts, and context, review question
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	This article is the protocol for the scoping review
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	P. 5 inclusion criteria
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	P. 6 Searches and study selection, Supplementary file 1, a sample of literature search with Boolean operators and truncation
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Supplementary file 1
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	P. 6 Study selection
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any	P.7 Data extraction and charting process, supplementary file 2 – data extraction instrument



SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
		processes for obtaining and confirming data from investigators.	
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	P. 5
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	NA. Quality appraisal will not be performed on studies in this scoping review.
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	To be conducted in the scoping review
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	To be conducted in the scoping review
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	To be conducted in the scoping review
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	NA
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	To be conducted in the scoping review
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	To be conducted in the scoping review
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	To be conducted in the scoping review
Limitations	20	Discuss the limitations of the scoping review process.	P.2
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	To be conducted in the scoping review
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	P.7

JB1 = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.



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3 † A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g.,
4 quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping
5 review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

6 ‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the
7 process of data extraction in a scoping review as data charting.

8 § The process of systematically examining research evidence to assess its validity, results, and relevance before
9 using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable
10 to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used
11 in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

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Creating dementia-friendly and inclusive communities for social inclusion: a scoping review protocol

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4 **Title: Creating dementia-friendly and inclusive communities for social inclusion: a scoping**
5 **review protocol**
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43 **Abstract**

44 **Introduction:** The number of people with dementia is increasing worldwide, with the majority of people
45 with dementia living at home in the community. The World Health Organization calls for global action on
46 the public health response to dementia. Social exclusion is commonly reported by people with dementia
47 and their families. Dementia-friendly and inclusive community has emerged as an idea that holds
48 potential to contribute to the mitigation of social exclusion. The objective of the scoping review is to
49 answer two questions: What social inclusion strategies that have been reported in the dementia-friendly
50 and inclusive communities' literature? What strategies for developing dementia-friendly and inclusive
51 communities that have shown to improve social inclusion?
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Methods and Analysis: This scoping review will follow the Joanna Briggs Institute scoping review methodology and will take place between April and September 2020. The proposed review will consider studies based in community settings with participants living at home with early to late stages of dementia and their families. This includes a three-step search strategy: (1) to identify keywords from MEDLINE and CINAHL; (2) to conduct a second search using all identified keywords and index terms across selected databases (MEDLINE, CINAHL, AgeLine, PsycINFO, Web of Science, ProQuest and Google); and (3) to hand-search the reference lists of all included articles and reports for additional studies. Further, we will search Google for grey literature on published organizational reports. Two researchers will screen titles and abstracts independently and then assess the full text of selected citations against inclusion criteria. Extracted data will be presented in a narrative accompanied by tables that reflect the objective of the review.

Ethics and Dissemination: As the methodology of this study consists of collecting data from publicly available articles, it does not require ethics approval. This scoping review provides an overview of current evidence on strategies that support dementia-friendly and inclusive communities for social inclusion. The findings will offer insights to inform strategies for education, practice, policy and future research. We will share the scoping review results through conference presentations and an open-access publication in a peer-reviewed journal.

Keywords: dementia-friendly community, dementia-inclusive community, dementia, social inclusion, scoping

Strengths and Limitations:

- People with lived experience, families of people with dementia, leaders of health organizations, and community representatives will be involved in conducting and disseminating the scoping review.
- This is a novel and timely topic to understand how dementia-friendly and inclusive community may support social inclusion among people with dementia living at home in the community.
- The results and recommendations of scoping reviews cannot be graded since methodological appraisal of the quality of included studies is not consistent with the Joanna Briggs Institute scoping review guidelines.
- Studies not published in English will be missed.
- Strategies for building dementia friendliness in hospitals and other formal healthcare settings will not be captured.

INTRODUCTION

The number of people with dementia is growing exponentially across the world. Globally, around 50 million people live with dementia; there are nearly 10 million new cases every year. [1] People with dementia and their informal caregivers face challenges that include stigma, social exclusion, difficulty accessing formal and informal support resources and financial pressures. The World Health Organization has declared dementia as a public health priority. [1] The global action plan calls for actions to address dementia as a public health priority, increase awareness of dementia, establish dementia-friendly initiatives, provide support for dementia carers, and conduct research and innovation. Social exclusion and isolation can have detrimental effects on mental and physical health, such as depression and cardiovascular health. [2] Current efforts to promote dementia-friendly and inclusive communities have the potential to promote social inclusion, change attitudes and behaviours, and support people with dementia to be engaged in community in meaningful ways. [3]

Dementia-Friendly and Inclusive Community, Social Inclusion

A dementia-friendly and inclusive community can be defined as a city, town or village where people with dementia are understood, respected and supported. [4] Social inclusion refers to a dynamic process where people engage with, and are part of, their social networks in the community to maintain meaningful social relations. [5] Social connection and a sense of belonging are essential to well-being and quality of life. [5] Purposeful connection, doing meaningful activities together, are important to a person with dementia and their families/care providers.[6,7] People with dementia can benefit from their local community network; social inclusion and social participation promote a sense of social citizenship, safety and contribution. [8] The existing literature suggests there is potential for dementia-friendly and inclusive community to support social inclusion.[9] Stigma is one of the key challenges that people with dementia face. Stigma and lack of understanding cause people in societies to behave in ways that focus on problems of the disease rather than supporting the abilities that people with dementia have.[10] Considering stigma and social exclusion are important issues for people with dementia living in the community, interventions that engage and include people with dementia in community activities seem vital to support people with dementia to remain living in their own homes for as long as possible.

The notion of dementia-friendly community has been drawn from the Age-Friendly Cities initiative of the World Health Organization. [11] Age-friendly communities involves bringing stakeholders together to help create more inclusive environments in local communities in order to promote active and healthy aging. [12] Age-friendly communities contribute to good health and allow people to continue to participate fully in society.[4] A similar guiding principle that dementia-friendly and age-friendly strategies both embody is - empowering local stakeholders to collaborate and contribute for social inclusion. Public education, reduction of stigma, and removal of barriers in physical and social environments are common themes in

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3 dementia-friendly initiatives as well. [13] Dementia advocates Rahman and Swaffer have criticized the
4 term 'dementia-friendly' for its implied focus on deficit, suggesting a sense of otherness identified with an
5 illness model, and thus they argue for an assets-based focus. [14] We acknowledge the need to shift the
6 attention to strengths and assets that people with dementia can bring. Thus, we use the term 'dementia-
7 friendly and inclusive" for the scoping review. While "dementia-friendly' is the most common term used in
8 the literature and government initiative, it is important to pay attention to language that promotes inclusion
9 and human rights, not deficits.

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14 In the UK, dementia-friendly and inclusive communities were found in regions with a large population of
15 people living with dementia. [15] Yet, people with dementia reported that they didn't know how to
16 contribute to their local community, and that they had an overriding sense of low expectation and low self-
17 belief. [16] As the development of dementia-friendly and inclusive community has the potential to
18 empower people with dementia, it is important to better understand what makes dementia-friendly and
19 inclusive communities effective. [17,18] In Australia, people with dementia identified six priorities in
20 creating dementia-friendly communities: increased public awareness and understanding of dementia,
21 access to social activities, support to stay at home, appropriate health care, transport; and improvements
22 to the physical environment.[19] Stigma was viewed as a key barrier to community engagement, thereby
23 leading to social isolation among people with dementia. [20] In Canada, the notion of social inclusion has
24 been underlined as essential for people with dementia. [5] The impact of both supportive physical and
25 social environments has been identified as vital to social inclusion, empowerment, and enablement for
26 people with dementia to contribute to and participate in society.[21,22] Active involvement of people with
27 dementia and their families is also considered to be a key enabler in the development of dementia-
28 friendly and inclusive community. [23] "Nothing about us without us" is a phrase borrowed from the
29 disability movement which has been frequently expressed by people with dementia in public campaigns.
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40 To date, knowledge about strategies that promote effective development of dementia-friendly and
41 inclusive communities remains limited, indicating that there is a need to identify enabling strategies to
42 inform education, practice, policy and future research.[24] In this scoping review study, 'strategy' refers to
43 an action plan and interventions conducted to achieve the goal of creating dementia-friendly and inclusive
44 communities. In June 2019, the Government of Canada released its national dementia strategy.
45 'Promoting social inclusion and dementia-inclusive communities' was one of the areas of focus in the
46 Canadian dementia strategy.[25] The Public Health Agency of Canada launched the Dementia
47 Community Investment, a four million dollar per year ongoing investment, which funds community-based
48 projects that seek to achieve the following: optimize the wellbeing of people with dementia and their
49 informal caregivers; increase public knowledge of dementia and its risk factors; undertake intervention
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3 research to assess the effectiveness of the program or initiative; and apply that knowledge to support
4 expansion of the project's reach to new communities, sectors, and populations.[11]
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7 A preliminary search of MEDLINE, CINAHL, PsycINFO, and the Joanna Briggs Institute (JBI) Database of
8 Systematic Reviews and Implementation Reports conducted on Sept 30, 2019 found no systematic
9 review examining strategies that support dementia-friendly and inclusive communities for social inclusion
10 in the community home settings.
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14 In an integrative review, Shannon et al. found eight papers that described the characteristics of
15 dementia-friendly communities. [23] Building on the work by Shannon et al., our scoping review aims to
16 offer three contributions. First, we will produce a robust synthesis of updated evidence; more studies and
17 reports have emerged in the last three years. The articles reported by Shannon et al. were published in
18 the year from 2011-16. Second, this scoping review will map accessible literature (including Google
19 search) to provide a comprehensive overview of evidence to inform education, practice, policy, and
20 further research. Third, by including patient and family partners in conducting the scoping review, we
21 increase the relevance, quality of the study, including transparency and accountability.[26] As pointed out
22 by the Joanna Briggs Institute, when a research topic is new and has not been fully established, scoping
23 reviews are useful to systematically map and synthesize the current state of knowledge.[27]
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30 The main objective of the scoping review is to chart the body of literature on strategies and impacts of
31 creating dementia-friendly and inclusive communities that support people with dementia and their informal
32 care providers.
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36 **Review Questions**

- 37 • What social inclusion strategies have been reported in the literature of dementia-friendly and
38 inclusive communities?
- 39 • What strategies for developing dementia-friendly and inclusive communities have shown to
40 improve social inclusion?
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45 **METHODS**

46 The proposed scoping review will be conducted in accordance with the Joanna Briggs Institute
47 methodology for scoping reviews.[27] This scoping study will take place between April and September
48 2020.
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52 **Inclusion Criteria**

53 **Participants**

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3 This review will include young and older people with dementia living at home in the community. Studies
4 that focus on neighbours, local citizens, public and private service providers, care providers and families
5 of people with dementia in the community that promote dementia-friendly community will also be
6 included.
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10 **Concept**

11 This scoping review aims to identify strategies for developing dementia-friendly and inclusive communities
12 that have shown to improve social inclusion. The core concept is strategy. Such strategies may include
13 public education activities that change attitudes and behaviours to reduce stigma in a community or any
14 interventions that create positive impact to improve social inclusion and social participation of people with
15 dementia. For example, any articles that report on public awareness initiatives, education and training
16 about dementia, development of physical environment guidelines will be considered. 'Impact' refers to a
17 broad range of changes that occur as a result of dementia-friendly and inclusive community activities. We
18 will examine information that reports reach, adoption and implementation.[28] Improved public knowledge
19 of dementia and increased social participation of people with dementia are examples of positive impact of
20 social inclusion.
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28 **Context**

29 Community in this review refers to people residing at home in a local geographical area. Studies in
30 targeted formal healthcare organizations such as long-term care facilities and hospitals will be not
31 considered in this review.
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35 **Types of Studies**

36 This scoping review will consider studies published in English with no time limit. A wide range of study
37 designs from randomized controlled trials to descriptive studies will be considered. All type of study
38 designs (quantitative and qualitative) will be considered for inclusion. This review will also consider
39 student theses published by universities.
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43 **Search Strategy**

44 As recommended in JBI review guidelines, we will apply the three-step search strategy.[29] The first step
45 is an initial limited search of at least two appropriate online databases relevant to the topic. An initial
46 limited search of MEDLINE and CINAHL will be conducted using the selected keywords: dementia or
47 Alzheimer, (community or communities) OR (city or cities) OR (neighborhood or neighbourhood) OR
48 (environment or environments), friendly or capable or inclusive or inclusion. The initial search will be
49 followed by analysis of the text words contained in the titles and abstracts of relevant articles, as well as
50 the index terms used to describe these articles. The second step involves using all identified keywords
51 and index terms, will then be undertaken and adapted for each included information source. Thirdly, the
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3 reference lists of all included articles and reports will be screened for additional studies. A full search
4 strategy for MEDLINE is included in. See supplementary file 1 for the selected keywords and details of
5 the three-step approach. We have worked and will continue to work with a gerontology librarian at the
6 university to refine the search strategy to ensure key articles are captured. The senior scientist (AP) in the
7 team is familiar with key literature and will provide guidance for specific reference search throughout the
8 process.
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12 13 **Information Sources**

14 The databases to be searched include MEDLINE, CINAHL, Ageline, PsycINFO, Web of Science and
15 ProQuest for thesis and dissertation. Google will be searched as well by using phrases, i.e., “dementia-
16 friendly” OR “dementia friendly” OR “dementia-inclusive” OR “dementia inclusive” OR
17 “dementia-capable” OR “dementia capable”.
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22 **Study Selection**

23 Following the search, all identified citations will be collated and uploaded into Mendeley and duplicates
24 removed. Titles and abstracts will then be screened by two independent researchers (LH and SL) for
25 assessment against the inclusion criteria for the review. Potentially relevant studies will be retrieved in full,
26 and their citation details imported into the Joanna Briggs Institute System for the Unified Management,
27 Assessment and Review of Information (JBI SUMARI) (Joanna Briggs Institute, Adelaide, Australia). The
28 full text of selected citations will be assessed in detail against the inclusion criteria by two independent
29 researchers. The first two authors will check with the gerontology librarian and senior scientist (AP) to
30 refine the searching and selecting process. Reasons for exclusion of full-text studies that do not meet the
31 inclusion criteria will be recorded and reported in the scoping review. Any disagreements that arise
32 among the reviewers at each stage of the study selection process will be resolved through discussion. If
33 consensus cannot be achieved, the senior scientist (AP) will facilitate discussion to foster the decision-
34 making process. The results of the search will be reported in full in the final report and presented in a
35 Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA-ScR) flow diagram.
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44 **Data Extraction**

45 Data will be extracted from papers included in the scoping review by two researchers using a data
46 extraction tool. The data extracted will include specific details about the year of publication, country,
47 setting, population, strategies and impacts related to dementia-friendly and inclusive communities that
48 support social inclusion. For example, in 2019, Phillipson et al reported successful strategies such as
49 education events co-designed and co-facilitated by people with dementia at Kiama in Australia.[13] The
50 quantitative data in survey (e.g., attitude and knowledge change) conducted with community members
51 will be extracted as impact. Data about the number of community members received education activities
52 will also be extracted as project reach under impact. We will also extract relevant qualitative responses,
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3 such as experiences and perspectives. A draft charting table is provided (see supplementary file 2). The
4 data extraction tool will be pilot-tested; two independent researchers will complete extraction from three
5 studies and compare results. The draft data extraction tool will be modified and revised as necessary
6 during the process of extracting data from each included study. Modifications will be detailed in the full
7 scoping review report. Based on the discussion in study team meeting, we are open to go back to any
8 included articles to further explore and present results beyond extracted data if needed. Any
9 disagreements that arise between the reviewers will be resolved through discussion. If consensus cannot
10 be reached, the senior scientist (AP) will be consulted.
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16 **Patient and Public Involvement**

17 Three patient partners (people with early stage of dementia – MG, JM, LJ) and four family partners
18 (people who have a family member with dementia – NH, LW, AB, CW) will be engaged in regular
19 meetings to discuss extracted data and validate study results. See their full names in acknowledgment.
20 Patient and family partners will review extracted data and full text articles. Each patient and family
21 partners will decide the number of articles that they would like to review. We anticipate about 3-5 articles
22 per person on average. Patient and family partners will receive a small honorarium, and they will be co-
23 authors of the next paper that reports the scoping study results. Patient and family partners were
24 recruited from a local community organization, the Community Engagement Advisory Network (CEAN).
25 More information about how CEAN supports patient and public involvement can be found at
26 <http://cean.vch.ca>. Also, we will invite organizational leaders in local health authorities and
27 representatives of local Alzheimer Society chapters to engage in a day-long workshop. If in-person
28 meeting is not possible due to the COVID-19 (Coronavirus) situation, we will engage stakeholders by
29 zoom, video-conferencing meeting. The aim of the workshop is to discuss input and seek feedback on the
30 scoping review results, with the goal of having these workshop participants disseminate the results on
31 their respective organizational websites and their networks of communication.
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40 **Ethics and Dissemination**

41 Research ethics approval and consent to participate is not required for this scoping review. The results
42 will be disseminated at regional, national, and international conferences. The findings will be made
43 accessible to health professionals, policy and decision makers, and the public.
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48 **Data Synthesis**

49 The extracted data and results will be presented in table to summarize and map the existing literature. A
50 narrative summary will accompany the tabled results to describe the characteristics of the literature on
51 dementia-friendly and inclusive community strategies that support social inclusion. The categories that will
52 be used for data presentation include: year of publication, country, context, population, intervention types,
53 enabling strategies and impacts related to dementia-friendly and inclusive communities that support
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social inclusion. The authors anticipate the findings will be a critical step in providing evidence-based guidance to inform future practice, policy and research.

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Contributors LH conceived the idea, developed the research protocol and methods, and drafted and edited the final manuscript. SL, RH, AP helped to refine and develop the research question and study methods and made meaningful contributions to the drafting and editing of the manuscript. All authors approved the final manuscript submitted.

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Competing interests None declared.

Patient consent Not required.

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Supplementary file 1: Search strategy

We have worked and will continue to work with a gerontology librarian at the university to refine the search strategy to ensure key articles are captured. Here is the plan.

We will apply the 3-step approach as outlined in the Joanna Briggs Institute Scoping Review Guideline.

Step 1: The initial search included two online databases relevant to the topic: MEDLINE & CINAHL

An example of the search in MEDLINE

#	Searches	Results
S1	dementia or Alzheimer	239,940
S2	(community or communities) OR (city or cities) OR (neighborhood or neighbourhood) OR (environment)	1,990,144
S3	Friendly or capable or inclusive or inclusion	546,629
S4	S1 AND S2 AND S3	1,029

This initial search is then followed by an analysis of the text words contained in the title and abstract of retrieved papers, and of the index terms used to describe the articles.

Step 2: A second search using all identified keywords and index terms will then be undertaken across all selected databases: MEDLINE, CINAHL, Ageline, PsycINFO, Web of Science, and ProQuest-Thesis and Dissertation.

2a) Search terms and their combinations in step 2

Dementia-friendly terms	Community terms	Social inclusion terms
Dementia-friendly	Community	Social inclusion
Dementia friendly	communities	Social inclusive
Dementia-inclusive	City	Social connection
Dementia inclusive	Cities	social participation
Dementia-capable	Neighborhood	
Dementia capable	Neighbourhood	
Dementia positive	Environment	
	Social environment	
	Built environment	
	Environmental design	

2b) Google will be used to search grey literature (i.e., organizational reports, newsletters, and other articles not indexed in a library database. For the Google search, we will perform phrase using the following terms

• (“dementia-friendly” OR “dementia friendly” OR “dementia-inclusive” OR “dementia inclusive” OR “dementia-capable” OR “dementia capable”)

Step 3: The resulting reference list of all identified reports and articles will be searched for additional studies. Google Scholar will be used to find published articles, organizational reports and related articles.

Supplementary file 2: Data extraction tool

Author, Year & country	Context or Setting	Population or Participants	Type of Article	Study design	Strategies	Impact

For peer review only

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	P.1 title
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	P.1-2 Abstract and article summary
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	P.3 Introduction
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	P. 5 Study objective, population, concepts, and context, review question
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	This article is the protocol for the scoping review
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	P. 5 inclusion criteria
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	P. 6 Searches and study selection, Supplementary file 1, a sample of literature search with Boolean operators and truncation
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Supplementary file 1
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	P. 6 Study selection
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any	P.7 Data extraction and charting process, supplementary file 2 – data extraction instrument



SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
		processes for obtaining and confirming data from investigators.	
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	P. 5
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	NA. Quality appraisal will not be performed on studies in this scoping review.
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	To be conducted in the scoping review
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	To be conducted in the scoping review
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	To be conducted in the scoping review
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	NA
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	To be conducted in the scoping review
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	To be conducted in the scoping review
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	To be conducted in the scoping review
Limitations	20	Discuss the limitations of the scoping review process.	P.2
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	To be conducted in the scoping review
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	P.7

JB1 = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.



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3 † A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g.,
4 quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping
5 review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).
6 ‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the
7 process of data extraction in a scoping review as data charting.
8 § The process of systematically examining research evidence to assess its validity, results, and relevance before
9 using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable
10 to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used
11 in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).
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14 *From:* Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-
15 ScR): Checklist and Explanation. *Ann Intern Med.* ;169:467–473. doi: 10.7326/M18-0850
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