



BMJ Open is committed to open peer review. As part of this commitment we make the peer review history of every article we publish publicly available.

When an article is published we post the peer reviewers' comments and the authors' responses online. We also post the versions of the paper that were used during peer review. These are the versions that the peer review comments apply to.

The versions of the paper that follow are the versions that were submitted during the peer review process. They are not the versions of record or the final published versions. They should not be cited or distributed as the published version of this manuscript.

BMJ Open is an open access journal and the full, final, typeset and author-corrected version of record of the manuscript is available on our site with no access controls, subscription charges or pay-per-view fees (<http://bmjopen.bmj.com>).

If you have any questions on BMJ Open's open peer review process please email info.bmjopen@bmj.com

BMJ Open

Collaboration and coordination of health and care services for older people with dementia by multidisciplinary health and care providers: a scoping review protocol

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2022-066578
Article Type:	Protocol
Date Submitted by the Author:	13-Jul-2022
Complete List of Authors:	Österholm, Johannes; Linköping University Faculty of Medicine Ann-Charlotte, Nedlund; Linköping University, Department of Health, Medicine and Caring Sciences Linköping, SE 581 83 Åsa, Larsson Ranada; Linköping University, Department of Health, Medicine and Caring Sciences Linköping, SE 581 83
Keywords:	HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Organisation of health services < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Dementia < NEUROLOGY

SCHOLARONE™
Manuscripts

Collaboration and coordination of health and care services for older people with dementia by multidisciplinary health and care providers: a scoping review protocol

Österholm Johannes^{1*} ORCID 0000-0002-6241-002

Nedlund Ann-Charlotte² ORCID 0000-0003-0204-4536

Larsson Ranada Åsa¹ ORCID 0000-0002-0761-1942

1 Linköping University, Department of Health, Medicine and Caring Sciences, Division of Prevention, Rehabilitation and Community Medicine (PRNV), Unit of occupational therapy

2 Linköping University, Department of Health, Medicine and Caring Sciences, Division of Society and Health

* corresponding author Johannes Österholm, Linköpings universitet, 581 83 Linköping Sweden. johannes.h.osterholm@liu.se

Word count 2710

Keywords: Alzheimer’s disease, care management, case management, Integrated care, Seamless care

ABSTRACT

Introduction: Collaboration and coordination of health and care services are key to catering for the diverse needs of a growing population of older people with dementia. When multidisciplinary health and care providers work together, they have the possibility to use resources in a fair, accurate, and effective way and thereby do the right thing, at the right time, for the right individual. The aim of this scoping review is to map how different care-providing agencies collaborate and coordinate health and care services for older people with dementia.

Methods and analysis: A scoping review will be carried out according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses - Scoping Review Extension guidelines. Systematic searches will be carried out in scientific databases. Studies published within the last 10 years will be included based on certain eligibility criteria. All included studies will be critically appraised using the Research Pyramid. Data from included studies will be charted and subjected to content analysis.

Ethics and dissemination: Ethics approval is not required for scoping reviews. The dissemination of findings will be conducted through conference presentations and publication in international scientific journals.

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Strengths and limitations of this study

- The methodology of the scoping review will be structured in accordance with the PRISMA-ScR.
- Several different databases – covering different scholarly disciplines of relevance for the aim of the scoping review – will be used to search for sources of evidence.
- Collaboration and coordination of care services are multifaceted concepts with various meanings and understandings; therefore, it is possible that relevant studies could be missed.

INTRODUCTION

Problems concerning fragmentation of the delivery of health and care services for older people represent an issue commonly discussed in different countries with various welfare systems [1-3]. The matter is not new but has attracted great attention in the wake of COVID-19, not least in the case of older people with multiple and complex care needs. Barriers to the successful collaboration and coordination of health and care services targeting older people have been described in previous literature [1-2] in terms of structural and organisational deficits in elder care systems, boundaries between various agencies and actors [4], and uncertainties regarding the division of responsibility between different agencies as stipulated in laws and regulations [5]. Accordingly, there is lack of clarity concerning which agency has the main responsibility and for what, how responsibility overlaps with that of other agencies, and how the care hand-over processes are managed and communicated between all involved parties in practice.

Collaboration amongst various agencies and the coordination of services have been pointed out as crucial for the accurate provision of health and care services for older people with multiple and complex care needs such as dementia. This has been highlighted by WHO [6], which describes coordination of care as: “a proactive approach to bringing together care professionals and providers to meet the needs of service users to ensure that they receive integrated, person-focused care across various settings.” (p. 9). Hence, coordination and collaboration of health and care services can be regarded as related to the provision of services both within the same and across various agencies. In the framework presented by WHO [7] on the integration of care for older people, it is stated that considerations and actions are needed at multiple levels to implement and integrate care for older people; on macro- (system level; e.g., available services, accountability systems, financing health and

care services, guidelines and regulations, national boards of directions), meso- (service level, e.g., coordination of services delivered by multidisciplinary providers), and micro level (person-centred goals; e.g., how to provide services to maximise the intrinsic capacity and functional abilities of the older person). Hence, the concept of collaboration and coordination of health and care services is multifaceted as it can refer to services provided by different professionals with various disciplinary backgrounds working either on the same or diverse levels (i.e. macro, meso, micro) and within the same agency or between different agencies.

When it comes to older people with a dementia diagnosis, the diagnosis and its diseases often imply multiple and complex health and care needs that require considerable support from different care-providing agencies [8]. As the number of older people with dementia is projected to increase on a global level, from 50 million cases in 2020 to 150 million cases in 2050 [9-10], the stress on welfare systems – which are challenged by prioritising due to limited resources – will surge [11]. Therefore, to use resources in a fair, appropriate, and effective way, and to do what is medically most appropriate for the specific individual in concern in the specific care setting, different care-providing agencies – with various responsibilities – must collaborate and coordinate their services. Collaboration and coordination between different agencies could be considered part of the solution [12] to overcoming the risk that people with dementia and their carers may not receive the formal support that they need or are entitled to [13]. Given the high level of agreement on its importance, the question remains: How do different care-providing agencies collaborate and coordinate health and care services for older people with dementia?

Previous reviews on coordination and collaboration regarding people with dementia

To our knowledge, there is at least one previous review summarising evidence of interventions aiming at coordinating health and care services for people with dementia [12]. Most other reviews do not single out a specific target group. In a scoping review, Røsvik et al., [14] mapped and examined research on how access and use of formal community services could be improved. They found five different types of interventions with a widely varied design: case management, monetary support, referral enhancing, awareness and information, and inpatient focus [14]. A variety of professions (e.g., social workers, nurses) or multidisciplinary teams are involved in the process of coordinating health and care services for people with dementia [12, 15-18]. The professionals' disciplinary background and the organisational affiliation have been described to have consequences for what is thought of as important when coordination of care is conducted for people with dementia. Furthermore, multidisciplinary teams working collaboratively could result in more efficient primary, secondary, and tertiary care for people with dementia [12]. When coordinating services for people with dementia, and information sharing between different agencies and multidisciplinary care providers it is vital to provide appropriate support, and hence the communication between different agencies and professionals has been studied (e.g., scheduled meetings, case conferences or web-based case files) [16-18]. Less is known about the actual collaboration and coordination taking place between different actors working together either at the same or different level in a welfare system (i.e. agency representatives, service providers, care units, between and amongst care teams) and what the consequences are for the individuals concerned and their significant others.

When it comes to the coordination of health and care services for older people with dementia, previous research has mostly been conducted from the perspective of case management, often also referred to as care management [14, 19]. Previous systematic reviews have described

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

case management as a complex intervention to identify and cater for various needs amongst people with dementia [16, 18] and to coordinate medical and community services [16]. However, case management, its process and implementation, may vary extensively in different countries due to different ways of organising support and services, management systems (including centralised vs. decentralised systems), funding policies, and also due to cultural variations governing the process [20]. In addition, in a systematic review, Saragih et al., [19] conclude that case management is implemented differently depending on the clinical setting. For example, the principles of care planning, implementation, coordination monitoring and evaluation in a primary care setting differed from memory clinics where additional support was provided, i.e. cognitive stimulation, stress management and psychological support [16, 19, 21]. A commonality of case management is that one key person coordinates and monitors all provided care support and services to the service user concerned [22]. The impact of case management is diverse, probably because the actual work the case manager carries out varies between different legislations and welfare systems, and hence there is no standard definition of case management in previous scholarly work [12, 18].

Accordingly, what we have seen is that even though there is a legal requirement in many countries for different agencies and various professionals to collaborate and coordinate their activities [7], this does not seem to achieve the expected result – to create good fair, accurate, and effective care for older people. This raises questions about the nature of the collaboration, for example in terms of the planning of the discharge process of older people with dementia from hospital to municipal health and social care, and how this could be improved. More evidence is needed on how different care-providing agencies collaborate and coordinate health and care services for people with dementia.

Review questions

The aim of this scoping review is to map how different care-providing agencies collaborate and coordinate health and care services for older people with dementia.

RQ1 What characterises collaboration and coordination between different care-providing agencies regarding people with dementia?

RQ2 What are the outcomes reported following collaboration and coordination of health and care services for people with dementia?

RQ3 What are the experiences described by different actors (i.e. agency representatives, service providers, service users, significant others) regarding collaboration and coordination of health and care services for people with dementia?

METHODS AND ANALYSIS

Study design

A scoping review was chosen to map existing research, and how the area of concern has been studied previously. Scoping reviews are intended to identify and analyse knowledge gaps and identify types of evidence in a certain field, which is in line with the aim of this study. A scoping review is suitable for clarifying concepts and characteristics of research regarding a certain area or topic, especially if the previous research includes both quantitative and qualitative data that can be difficult to synthesise in a meta-analysis [23].

Eligibility criteria

The eligibility criteria for the present scoping review follow the PRIMSA-ScR [24-25] and will be structured in regard to participants, concept, and context. Furthermore, study

characteristics (i.e. years considered, language, and publication status) will be used as eligibility criteria for the inclusion of studies in this scoping review.

Participants

This scoping review concerns the collaboration and coordination of health and care services for older people with dementia. Hence, the aim itself suggests that the participants targeted for this review are very different with multidisciplinary professional backgrounds. In previous dementia research, there has been a tendency to exclude the person with dementia [26] and to focus on the professionals’ or the significant others’ perspective. In this scoping review, studies will be included if the study concerns collaboration and coordination of health or care services for older people (i.e. 60 years or older) with dementia. Hence, multiple different participants or actors could be addressed in the included studies, such as multidisciplinary professionals representing various agencies or the same one, politicians, people with dementia and their significant others. Dementia is an umbrella concept including several different diagnoses [8]. In this scoping review, different diagnoses of dementia, as described in ICD-10 and DSM-V, will be included.

Concept

In this scoping review, a broad understanding of the concept's *collaboration* and *coordination* of health and care services will be used. The concepts of collaboration and coordination are key elements in WHO’s [7] description of integrated care, namely an “approach to bringing together care professionals and providers to meet the needs of service users” (p.p. 9) [6]. These care professionals and providers are active at the same or various levels (i.e. macro, meso, micro) in the welfare system and represent either the same or different agencies when they work with a person with dementia.

Context

This scoping review will include coordination and collaboration of health and care services provided by different actors working at the same or different care agencies at macro, meso, or micro levels in welfare systems. No limits will be set in regard to legislative context or countries.

Types of studies

Eligible studies for this scoping review will be empirical studies published in peer-reviewed journals. Studies conducted with qualitative, quantitative, or mixed methodology will be included. Due to feasibility reasons, only studies published in English will be considered.

Study protocols, reviews, letters to editors, opinions, doctoral dissertations, and conference abstracts will be excluded. A 10-year limit considering the publication date of studies will be applied.

Search strategy

This scoping review aims to identify published empirical studies. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist [24] will be used for this scoping review. How to conduct a scoping review in relation to PRISMA-ScR has been further developed by the Joanna Briggs Institute (JBI).

Thereby, PRISMA-ScR and the methodology proposed by JBI [25] will be used. The methodology proposed by the JBI consists of a three-step search strategy that will be followed. In accordance with the first step, an initial limited search was conducted in PubMed and Cinahl. The titles, abstracts, and indexing terms of the articles identified through this

search were analysed to provide search terms for the final search. This analysis and identification of search terms were conducted by all authors jointly and discussed until consensus was reached. Appendix 1 presents a sample of the initial search strategy in PubMed. In the second step a search across all chosen databases will be conducted using all identified search terms. The search will be conducted in PubMed, Cinahl, Embase, PsychInfo, Scopus and Web of Science. In the last step, the reference list of all included studies will be screened for additional studies, and a citation search [27], based on the included studies will be conducted to include relevant studies in accordance with the above-described eligibility criteria. No search for grey literature is currently planned but may be considered at a later stage of the process.

Selection of sources of evidence

The study selection process will be conducted by two senior researchers (JÖ and ÅLR). All potential studies will be imported to an Endnote 20 library. Endnote will be used to identify and remove duplicates of studies. JÖ and ÅLR will then separately conduct a study selection based on titles, abstracts, and full text screening. After this screening for potential studies to include, all included studies will then be retrieved in full text and imported to Endnote 20. A full text reading will be conducted to ensure that the studies are relevant in accordance with the eligibility criterion of this scoping review. Potential disagreements during the study selection process will be resolved through consultation and discussion with AN. A list of studies excluded after full text reading will be organised and distributed on the request of potential readers of the finalised scoping review. To structure the reporting of the full search and the study selection process, a PRISMA flow diagram will be used [27].

Data charting process

ÅLR and JÖ will have the main responsibility for extracting data from the studies included, and any disagreement will be resolved through discussions and consultations with AN. The data extraction will be recorded in a Microsoft Excel spreadsheet. A preliminary draft of the spreadsheet can be found in Appendix 2. The data subject for extraction has been inspired by the JBI manual [25] and the spreadsheet includes: 1) basic characteristics of the included studies (author(s), year of publication, origin/country of origin, aims/purposes, and methodology/method); 2) different stakeholders represented/presented in the study (i.e. from which actors' perspective is coordination and collaboration studied, who are the actors participating in the study); 3) intervention or model of collaboration or coordination; 4) outcome or key findings of the intervention/model. During the actual data extraction and data analysis this spreadsheet could be modified to include other aspects needed to answer the aim and research question of the scoping review.

Data dissemination, critical appraisal, and synthesis

Data analysis and the presentation of findings for this scoping review will be conducted in three stages. Firstly, a summary of basic characters will be presented in tabular format and in running text [25]. Secondly, all included studies will be critically appraised using the Research Pyramid (ÅLR)[28]. This will be done at an abstract level of the included studies and presented in a tabular format. According to the JBI recommendation, critical appraisal of the evidence is not mandatory but if conducted it could either be based on the title, abstract or full text of included studies [25]. Nonetheless, a critical appraisal based on the Research Pyramid [28] provides a mapping of what has been done in the research area before, and what evidence gaps need to be addressed in future studies. Lastly, a conventional content analysis [29] will be used inductively to identify and map collaboration and coordination in dementia elder care as presented in the included studies. The content analysis is intended to be

inductive and descriptive [30] as scoping reviews usually do not synthesise the results of the included studies [25]. JÖ and AN will have the main responsibility for conducting the content analysis of extracted data from the included studies, ÅLR will be consulted throughout this analytical process.

Patient and public involvement

No patient involved.

Ethics and dissemination

This scoping review does not require approval from a human research ethics authority as it involves neither human participants nor unpublished secondary data. The findings will be disseminated through conference presentations and publications in scientific journals.

AUTHOR’S CONTRIBUTIONS

All authors have been involved in the conceptualisation. JÖ has taken the lead in designing the methodology for the reported scoping review and in authoring this protocol. Both ÅLR and AN have participated actively in the design of the methodology of the scoping review and in writing the protocol.

FUNDING STATEMENTS

This scoping review is financed by the Swedish Council for Working Life and Social Research (grant # STY-2021/0005 Dnr: 2021/01786).

COMPETING INTERESTS STATEMENT

The authors have no conflicts of interest to report.

REFERENCES

- 1 Bångsbo A, Dunér A, Dahlin-Ivanoff S, et al. Barriers for Inter-Organisational Collaboration: What Matters for an Integrated Care Programme?. *Inter J Integrated Care*. 2022;22:22. DOI: <http://doi.org/10.5334/ijic.6005>
- 2 Lyngsø AM, Godtfredsen NS, Frølich A. Interorganisational Integration: Healthcare Professionals' Perspectives on Barriers and Facilitators within the Danish Healthcare System. *Inter J Integrated Care*. 2016;16(1):4. DOI: <http://doi.org/10.5334/ijic.2449>
- 3 Lau JY, Wong EL, Chung RY, et al. Collaborate across silos: Perceived barriers to integration of care for the elderly from the perspectives of service providers. *Int J Health Plann Manage*. 2018 Apr 27. doi: 10.1002/hpm.2534.
- 4 SOU (2020:80) Äldreomsorgen under pandemin [Elder care during the pandemic] Swedish.
- 5 Nedlund AC, Taghizadeh Larsson A. "To protect and to support: How citizenship and self-determination are legally constructed and managed in practice for people living with dementia in Sweden." *Dementia*. 2016;15(3): 343-357.
- 6 World Health Organization [WHO]. Continuity and coordination of care. A practice brief to support implementation of the WHO Framework on integrated people-centred health services. Geneva; WHO;2018.
- 7 World Health Organization [WHO]. Integrated care for older people (ICOPE) implementation framework: guidance for systems and services. Geneva;WHO; 2019.
- 8 Marcusson J, Blennow K, Skoog I, et al. Alzheimers sjukdom och andra kognitiva sjukdomar. Stockholm: Liber; 2011.

9 World Health Organization [WHO]. World report on ageing and health. Switzerland: WHO; 2015.

10 World Health Organization [WHO]. Risk reduction of cognitive decline and dementia: WHO guidelines. Switzerland: WHO; 2019.

11 Christensen K, Doblhammer G, Rau R, et al. Ageing populations: the challenges ahead. *Lancet* (London, England), 2009;374(9696):1196–1208. [https://doi.org/10.1016/S0140-6736\(09\)61460-4](https://doi.org/10.1016/S0140-6736(09)61460-4)

12 Backhouse A, Richards DA, McCabe R, et al. Stakeholders perspectives on the key components of community-based interventions coordinating care in dementia: a qualitative systematic review. *BMC health services research*, 2017;17(1); 767. <https://doi.org/10.1186/s12913-017-2725-y>

13 Brodaty H, Thomson C, Thompson C, et al. Why caregivers of people with dementia and memory loss don't use services. *Int J Geriatr Psychiatry*. 2005;Jun;20(6):537-46. doi: 10.1002/gps.1322.

14 Røsvik J, Michelet M, Engedal K, et al. Interventions to enhance access to and utilization of formal community care services for home dwelling persons with dementia and their informal carers. A scoping review. *Aging Ment Health*. 2020 Feb;24(2):200-211. doi:10.1080/13607863.2018.1523876.

15 Tam-Tham H, Cepoiu-Martin M, Ronksley PE, et al. Dementia case management and risk of long-term care placement: a systematic review and meta-analysis. *Int J Geriatr Psychiatry*. 2013Sep;28(9):889-902. doi: 10.1002/gps.3906

16 Khanassov V, Vedel I. Family physician–case manager collaboration and needs of patients with dementia and their caregivers: a systematic mixed studies review. *Ann Fam Med*, 2016;14(2):166-177; DOI: <https://doi.org/10.1370/afm.1898>

17 Khanassov V, Vedel I, Pluye P. Barriers to implementation of case management for patients with dementia: a systematic mixed studies review. *Ann Fam Med*. 2014 Sep-Oct;12(5):456-65. doi: 10.1370/afm.1677.

18 Schiller C, Grünzig M, Heinrich S, et al. Case management for people with dementia living at home and their informal caregivers: A scoping review. *Health Soc Care Community*, 2021;1–21.

19 Saragih ID, Tonapa SI, Lin CJ, et al. Effects of case management intervention for people with dementia and their carers: A systematic review and meta-analysis of experimental studies. *Int J Nurs Stud*. 2021 Sep;121:104012. doi: 10.1016/j.ijnurstu.2021.104012.

20 Reilly S, Miranda-Castillo C, Malouf R, et al. Case management approaches to home support for people with dementia. *Cochrane Database Syst Rev*. 2015 Jan 5;1(1):CD008345. doi: 10.1002/14651858.CD008345.pub2.

21 Belle S, Burgio L, Burns R, et al. Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: a randomized, controlled trial. *Ann intern med* 2006;145(10):727-738.

22 Verkade P, van Meijel B, Brink C, et al. Delphi research exploring essential components and preconditions for case management in people with dementia. *BMC Geriatrics*, 2010;10(1);54.

- 23 Tricco AC, Lillie E, Zarin W, et al. A scoping review on the conduct and reporting of scoping reviews. *BMC Med Res Method*. 2016;16:15 DOI 10.1186/s12874-016-0116-4
- 24 Tricco AC, Lillie E, Zarin W, et al. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. *Ann Intern Med*; 2018.169(7):467-73.
- 25 Peters MDJ, Godfrey C, McInerney P, et al. Chapter 11: Scoping Reviews (2020 version). In: Aromataris E, Munn Z (Editors). *JBIM Manual for Evidence Synthesis*, JBI, 2020. Available from <https://synthesismanual.jbi.global>. <https://doi.org/10.46658/JBIMES-20-12>
- 26 Read, ST, Toye C, Wynaden D. The participation of people with dementia in the planning of their care and support: An integrative literature review. *Dementia*, 2020;19(3): 691-707. DOI: 10.1177/1471301218784806
- 27 Page M, McKensy J, Bossuyt P, et al., The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *Int J Surgery*. 2021;88.
- 28 Tomlin, G, Borgetto B. Research Pyramid: A new evidence-based practice model for occupational therapy. *Amer J Occup Ther*, 2011;65:189–196. doi: 10.5014/ajot.2011.000828
- 29 Ritchie J, Lewis J. Qualitative Research Practice: A Guide for Social Science Student and Researchers. London: Sage; 2003.
- 30 Olding M, McMillan S, Reeves S, et al. Patient and family involvement in adult critical and intensive care settings: a scoping review. *Health Expectation*. 2016;19: 1183-1202.

Appendix 1: Search strategy

Date searched: February 24, 2022

Alzheimer disease[MeSH Major Topic]) OR (Alzheimer disease[MeSH Terms])) OR
 (Alzheimer*[Title/Abstract])) OR (((Frontotemporal Lobar Degeneration[MeSH Major
 Topic]) OR (Frontotemporal Lobar Degeneration[MeSH Terms])) OR (Frontotemporal Lobar
 Degeneration[Title/Abstract])) OR (Frontotemporal dementia[MeSH Major Topic])) OR
 (Frontotemporal dementia[MeSH Terms])) OR (((Lewy Body Disease[MeSH Major Topic])
 OR (Lewy Body Disease[MeSH Terms])) OR (Lewy Body*[Title/Abstract])) OR (Lewy
 bodie*[Title/Abstract])) OR (((Vascular dementia[MeSH Major Topic]) OR (Vascular
 dementia[MeSH Terms])) OR (((dementia[MeSH Major Topic]) OR (Dementia[MeSH
 Terms])) OR (Dement*[Title/Abstract])) OR (Senile*[Title/Abstract])) AND
 (((((((((((health coord*[Title/Abstract]) OR (care coord*[Title/Abstract])) OR (care
 collab*[Title/Abstract])) OR (health collab*[Title/Abstract])) OR (health
 manage*[Title/Abstract])) OR (care manage*[Title/Abstract])) OR (Case
 Manage*[Title/Abstract])) OR (Case Management[MeSH Major Topic])) OR (Case
 Management[MeSH Terms]) OR (integrated care*[Title/Abstract])) OR (integrated health
 [Title/Abstract])) OR (comprehensive care [Title/Abstract])) OR (seamless care*
 [Title/Abstract])) OR (transmural care[Title/Abstract]))

Appendix 2: Data extraction table

Study reference	Origin/country of origin	Aims/purposes	Methodology/ Design	Participants	Stakeholder	Intervention/ model	Key outcome/ key findings	Evidence grading

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.	
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.	
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.	
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.	
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.	
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.	
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.	
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	
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 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.	
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).	
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
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.	
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	
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.	
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	
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.	
Limitations	20	Discuss the limitations of the scoping review process.	
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.	
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.	

JB I = 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.

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

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

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

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. Ann Intern Med. 2018;169:467–473. doi: 10.7326/M18-0850.

BMJ Open

Collaboration and coordination of health and care services for older people with dementia by multidisciplinary health and care providers: a scoping review protocol

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2022-066578.R1
Article Type:	Protocol
Date Submitted by the Author:	25-Nov-2022
Complete List of Authors:	Österholm, Johannes; Linköping University Faculty of Medicine Ann-Charlotte, Nedlund; Linköping University, Department of Health, Medicine and Caring Sciences Linköping, SE 581 83 Åsa, Larsson Ranada; Linköping University, Department of Health, Medicine and Caring Sciences Linköping, SE 581 83
Primary Subject Heading:	Health services research
Secondary Subject Heading:	Evidence based practice
Keywords:	HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Organisation of health services < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Dementia < NEUROLOGY

SCHOLARONE™
Manuscripts

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

**Collaboration and coordination of health and care services for older people
with dementia by multidisciplinary health and care providers: a scoping
review protocol**

Österholm Johannes^{1*} ORCiD 0000-0002-6241-002

Nedlund Ann-Charlotte² ORCiD 0000-0003-0204-4536

Larsson Ranada Åsa¹ ORCiD 0000-0002-0761-1942

1 Linköping University, Department of Health, Medicine and Caring Sciences, Division of Prevention, Rehabilitation and Community Medicine (PRNV), Unit of occupational therapy

2 Linköping University, Department of Health, Medicine and Caring Sciences, Division of Society and Health, Unit of Health Care Analysis

* corresponding author Johannes Österholm, Linköpings universitet, 581 83 Linköping Sweden. johannes.h.osterholm@liu.se

Word count 2710

Keywords: Alzheimer’s disease, care management, case management, Integrated care, Seamless care

ABSTRACT

Introduction: Collaboration and coordination of health and care services are key to catering for the diverse needs of a growing population of older people with dementia. When multidisciplinary health and care providers work together, they have the possibility to use resources in a fair, accurate, and effective way and thereby do the right thing, at the right time, for the right individual. The aim of this scoping review is to map how different care-providing agencies collaborate and coordinate health and care services for older people with dementia.

Methods and analysis: A scoping review will be carried out following the proposed methodology by JBI and reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses - Scoping Review Extension guidelines. Systematic searches will be carried out in scientific databases. Studies published within the last 10 years will be included based on certain eligibility criteria. All included studies will be critically appraised using the Research Pyramid. Data from included studies will be charted and subjected to content analysis.

Ethics and dissemination: Ethics approval is not required for scoping reviews. The dissemination of findings will be conducted through conference presentations and publication in international scientific journals.

Strengths and limitations of this study

- The methodology of the scoping review will be reported in accordance with the PRISMA-ScR.
- Several different databases – covering different scholarly disciplines of relevance for the aim of the scoping review – will be used to search for sources of evidence.
- Collaboration and coordination of care services are multifaceted concepts with various meanings and understandings; therefore, it is possible that relevant studies could be missed.
- Only studies published in English language will be included; therefore, it is possible that relevant studies published in other languages could be missed.

INTRODUCTION

Problems concerning fragmentation of the delivery of health and care services for older people represent an issue commonly discussed in different countries with various welfare systems [1-3]. The matter is not new but has attracted great attention in the wake of COVID-19, not least in the case of older people with multiple and complex care needs. Barriers to the successful collaboration and coordination of health and care services targeting older people have been described in previous literature [1-2] in terms of structural and organisational deficits in elder care systems, boundaries between various agencies and actors [4], and uncertainties regarding the division of responsibility between different agencies as stipulated in laws and regulations [5]. Accordingly, there is lack of clarity concerning which agency has the main responsibility and for what, how responsibility overlaps with that of other agencies, and how the care hand-over processes are managed and communicated between all involved parties in practice.

Collaboration amongst various agencies and the coordination of services have been pointed out as crucial for the accurate provision of health and care services for older people with multiple and complex care needs such as dementia. This has been highlighted by the World Health Organization (WHO) [6], which describes coordination of care as: “a proactive approach to bringing together care professionals and providers to meet the needs of service users to ensure that they receive integrated, person-focused care across various settings.” (p. 9). Hence, coordination and collaboration of health and care services can be regarded as related to the provision of services both within the same and across various agencies. In the framework presented by WHO [7] on the integration of care for older people, it is stated that considerations and actions are needed at multiple levels to implement and integrate care for older people; on macro- (system level; e.g., available services, accountability systems, financing health and care services, guidelines and regulations, national boards of directions), meso- (service level, e.g., coordination of services delivered by multidisciplinary providers), and micro level (person-centred goals; e.g., how to provide services to maximise the intrinsic capacity and functional abilities of the older person). Accordingly, collaboration and coordination of health and care services can refer to services provided by different professionals with various disciplinary backgrounds working either on the same or diverse levels (i.e. macro, meso, micro) and within the same agency or between different agencies. Collaboration and coordination are therefore important aspects to achieve integrated care amongst multiple care providers, within interdisciplinary teams or across care settings or sectors to improve patient’s experience and outcomes of care.

When it comes to older people with a dementia diagnosis, the diagnosis and its diseases often imply multiple and complex health and care needs that require considerable support from

different care-providing agencies [8]. As the number of older people with dementia is projected to increase on a global level, from 50 million cases in 2020 to 150 million cases in 2050 [9-10], the stress on welfare systems – which are challenged by prioritising due to limited resources – will surge [11]. Therefore, to use resources in a fair, appropriate, and effective way, and to do what is most appropriate for the specific individual’s concerns in the specific care setting, different care-providing agencies – with various responsibilities – must collaborate and coordinate their services. Collaboration and coordination between different agencies could be considered part of the solution [12] to overcoming the risk that people with dementia and their carers may not receive the formal support that they need or are entitled to [13]. Given the high level of agreement on its importance, the question remains: How do different care-providing agencies collaborate and coordinate health and care services for older people with dementia?

Previous reviews on coordination and collaboration regarding people with dementia

To our knowledge, there is one previous review summarising evidence of interventions aiming at coordinating health and care services for people with dementia [12]. In a previous scoping review, Røsvik et al., [14] mapped and examined research on how access and use of formal community services could be improved. They found five different types of interventions with a widely varied design: case management, monetary support, referral enhancing, awareness and information, and inpatient focus [14]. A variety of professions (e.g., social workers, nurses) or multidisciplinary teams are involved in the process of coordinating health and care services for people with dementia [12, 15-18]. The professionals’ disciplinary background and the organisational affiliation have been described to have consequences for what is thought of as important when coordination of care is conducted for people with dementia. Furthermore, multidisciplinary teams working collaboratively could

1
2
3 result in more efficient primary, secondary, and tertiary care for people with dementia [12].

4
5 When coordinating services for people with dementia, and information sharing between
6
7 different agencies and multidisciplinary care providers it is vital to provide appropriate
8
9 support, and hence the communication between different agencies and professionals has been
10
11 studied (e.g., scheduled meetings, case conferences or web-based case files) [16-18]. Less is
12
13 known about the actual collaboration and coordination taking place between different actors
14
15 working together either at the same or different level in a welfare system (i.e. agency
16
17 representatives, service providers, care units, between and amongst care teams) and what the
18
19 consequences are for the individuals concerned and their significant others.
20
21
22
23
24
25

26 When it comes to the coordination of health and care services for older people with dementia,
27
28 previous research has mostly been conducted from the perspective of case management, often
29
30 also referred to as care management [14, 19]. Previous systematic reviews have described
31
32 case management as a complex intervention to identify and cater for various needs amongst
33
34 people with dementia [16, 18] and to coordinate medical and community services [16].
35
36

37 However, case management, its process and implementation, may vary extensively in
38
39 different countries due to different ways of organising support and services, management
40
41 systems (including centralised vs. decentralised systems), funding policies, and also due to
42
43 cultural variations governing the process [20]. In addition, in a systematic review, Saragih et
44
45 al., [19] conclude that case management is implemented differently depending on the clinical
46
47 setting. For example, the principles of care planning, implementation, coordination
48
49 monitoring and evaluation in a primary care setting differed from memory clinics where
50
51 additional support was provided, i.e. cognitive stimulation, stress management and
52
53 psychological support [16, 19, 21]. A commonality of case management is that one key
54
55 person coordinates and monitors all provided care support and services to the service user
56
57
58
59
60

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

concerned [22]. The impact of case management is diverse, probably because the actual work the case manager carries out varies between different legislations and welfare systems, and hence there is no standard definition of case management in previous scholarly work [12, 18].

Even though there is a legal requirement in many countries for different agencies and various professionals to collaborate and coordinate their activities [7], this does not seem to achieve the expected result – to create fair, accurate, and effective provision of care for older people. This raises questions about the nature of the collaboration, for example in terms of the planning of the discharge process of older people with dementia from hospital to municipal health and social care, and how this could be improved. More evidence is needed on how different care-providing agencies collaborate and coordinate health and care services for people with dementia.

Review questions

The aim of this scoping review is to map how different care-providing agencies collaborate and coordinate health and care services for older people with dementia.

- RQ1 What characterises collaboration and coordination between different care-providing agencies regarding people with dementia?
- RQ2 What are the outcomes reported following collaboration and coordination of health and care services for people with dementia?
- RQ3 What are the experiences described by different actors (i.e. agency representatives, service providers, service users, significant others) regarding collaboration and coordination of health and care services for people with dementia?

METHODS AND ANALYSIS

Study design

A scoping review was chosen to map existing research, and how the area of concern has been studied previously. Scoping reviews are intended to identify and analyse knowledge gaps and identify types of evidence in a certain field, which is in line with the aim of this study. In contrary to systematic reviews, where the intention often is to identify or investigate conflicting results or guide decision-making, a scoping review is suitable for clarifying concepts and characteristics of research regarding a certain area or topic. Especially if the previous research includes both quantitative and qualitative data that can be difficult to synthesise in a meta-analysis [23]. The findings of the scoping review will be finalized in April 2023.

Eligibility criteria

The eligibility criteria for the present scoping review follow the PRIMSA-ScR [24-25] and will be structured in regard to participants, concept, and context. Furthermore, study characteristics (i.e. years considered, language, and publication status) will be used as eligibility criteria for the inclusion of studies in this scoping review.

Participants

This scoping review concerns the collaboration and coordination of health and care services for older people with dementia. Hence, the aim itself suggests that the participants targeted for this review are very different with multidisciplinary professional backgrounds. In previous dementia research, there has been a tendency to exclude the person with dementia [26] and to focus on the professionals' or the significant others' perspective. In this scoping review, studies will be included if the study concerns collaboration and coordination of health or care

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

services for older people (i.e. 60 years or older) with dementia. Hence, multiple different participants or actors could be addressed in the included studies, such as multidisciplinary professionals representing various agencies or the same one, politicians, people with dementia and their significant others. Dementia is an umbrella concept including several different diagnoses [8]. In this scoping review, different diagnoses of dementia, as described in ICD-10 and DSM-V, will be included.

Concept

In this scoping review, a broad understanding of *collaboration* and *coordination* of health and care services will be used. The terms collaboration and coordination are key elements in WHO’s [7] description of integrated care, namely an “approach to bringing together care professionals and providers to meet the needs of service users” (p.p. 9) [6]. By that, we will use an explorative approach, implying that we will inductively find out what others have discussed and presented in relation to these terms rather than depart from pre-defined concepts.

Context

This scoping review will include coordination and collaboration of health and care services provided by different actors working at the same or different care agencies at macro, meso, or micro levels in welfare systems. No limits will be set in regard to legislative context or countries.

Types of studies

Eligible studies for this scoping review will be empirical studies published in peer-reviewed journals. Studies conducted with qualitative, quantitative, or mixed methodology will be included. Due to feasibility reasons, only studies published in English will be considered.

Study protocols, reviews, letters to editors, opinions, doctoral dissertations, and conference abstracts will be excluded. A 10-year limit considering the publication date of studies will be applied (i.e., 2012 and forward) to include contemporary studies about this practice.

Search strategy

This scoping review aims to identify published empirical studies. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist [24] will be used for this scoping review. The scoping review methodology has been further developed by the Joanna Briggs Institute (JBI). Thereby, PRISMA-ScR reporting guidelines and the methodology proposed by JBI [25] will be used. The methodology proposed by the JBI consists of a three-step search strategy that will be followed. In the first step, an initial limited search was conducted in PubMed and Cinahl. The titles, abstracts, and indexing terms (i.e., MeSH-terms, key words) of the articles identified through this limited search were analysed to provide search terms for the final search which will be conducted in the second step. This analysis and identification of search terms were conducted by all authors jointly and discussed until consensus was reached. During this initial limited search, a librarian serving the Medical Faculty at Linköping University was consulted. Appendix 1 presents a sample of the initial search strategy in PubMed. In the second step a search across all chosen databases will be conducted using all identified search terms. The search will be conducted in PubMed, Cinahl, Embase, PsychInfo, Scopus and Web of Science. In the last step, the reference list of all included studies will be screened for additional studies, and a citation search [27], based on the included studies will be conducted to include relevant studies in accordance with the above-described eligibility criteria. No search for grey

literature is currently planned but may be considered at a later stage of the process if few studies are included based on the data base search.

Selection of sources of evidence

The study selection process will be conducted by two senior researchers (JÖ and ÅLR). All potential studies will be imported to an Endnote 20 library. Endnote will be used to identify and remove duplicates of studies. JÖ and ÅLR will then separately conduct a study selection based on titles, abstracts, and full text screening. After this screening for potential studies to include, all included studies will then be retrieved in full text and imported to Endnote 20. A full text reading will be conducted to ensure that the studies are relevant in accordance with the eligibility criterion of this scoping review. Potential disagreements during the study selection process will be resolved through consultation and discussion with AN. A list of studies excluded after full text reading will be organised and distributed on the request of potential readers of the finalised scoping review. To structure the reporting of the full search and the study selection process, a PRISMA flow diagram will be used [27].

Data charting process

ÅLR and JÖ will have the main responsibility for extracting data from the studies included, and any disagreement will be resolved through discussions and consultations with AN. The data extraction will be recorded in a Microsoft Excel spreadsheet. A preliminary draft of the spreadsheet can be found in Appendix 2. The data subject for extraction has been inspired by the JBI manual [25] and the spreadsheet includes: 1) basic characteristics of the included studies (author(s), year of publication, origin/country of origin, aims/purposes, and methodology/method); 2) different stakeholders represented/presented in the study (i.e. from which actors' perspective is coordination and collaboration studied, who are the actors

participating in the study); 3) intervention or model of collaboration or coordination; 4) outcome or key findings of the intervention/model. During the actual data extraction and data analysis this spreadsheet could be modified to include other aspects needed to answer the aim and research question of the scoping review.

Data dissemination, critical appraisal, and synthesis

Data analysis and the presentation of findings for this scoping review will be conducted in three stages. Firstly, a summary of basic characteristics will be presented in tabular format and in running text [25]. Secondly, all included studies will be critically appraised using the Research Pyramid (ÅLR) [28]. This will be done at an abstract level of the included studies and presented in a tabular format. According to the JBI recommendation, critical appraisal of the evidence is not mandatory but if conducted it could either be based on the title, abstract or full text of included studies [25]. Nonetheless, a critical appraisal based on the Research Pyramid [28] provides a mapping of what has been done in the research area before, and what evidence gaps need to be addressed in future studies. Lastly, a conventional content analysis [29] will be used inductively to identify and map collaboration and coordination in dementia elder care as presented in the included studies. The three research questions will be addressed all together in the content analysis. The content analysis is intended to be inductive and descriptive [30] as scoping reviews usually do not synthesise the results of the included studies [25]. Thereby, no existing theoretical framework will be used in the analytical process. Coding will be conducted on the extracted data independently by members of the research group. Based on these codes, categories (and potential sub-categories) of relevance will be compiled to present how different care-providing agencies collaborate and coordinate health and care services for older people with dementia. Discussions amongst all members of the research group will occur continuously throughout the analytical process to resolve potential

diversities until consensus is reached about the analysis. All authors will share the responsibility for conducting the content analysis.

Patient and public involvement

No patient or public involvement.

Ethics and dissemination

This scoping review does not require approval from a human research ethics authority as it involves neither human participants nor unpublished secondary data. The findings will be disseminated through conference presentations and publications in scientific journals.

AUTHOR’S CONTRIBUTIONS

All authors have been involved in the conceptualisation. JÖ has taken the lead in designing the methodology for the reported scoping review and in authoring this protocol. Both ÅLR and AN have participated actively in the design of the methodology of the scoping review and in writing the protocol.

FUNDING STATEMENTS

This scoping review is financed by the Swedish Council for Working Life and Social Research (grant # STY-2021/0005 Dnr: 2021/01786).

COMPETING INTERESTS STATEMENT

The authors have no conflicts of interest to report.

REFERENCES

1
2
3
4 1 Bångsbo A, Dunér A, Dahlin-Ivanoff S, et al. Barriers for Inter-Organisational
5 Collaboration: What Matters for an Integrated Care Programme?. *Inter J Integrated Care*.
6 2022;22:22. DOI: <http://doi.org/10.5334/ijic.6005>
7
8
9

10
11 2 Lyngsø AM, Godtfredsen NS, Frølich A. Interorganisational Integration: Healthcare
12 Professionals' Perspectives on Barriers and Facilitators within the Danish Healthcare System.
13 *Inter J Integrated Care*. 2016;16(1):4. DOI: <http://doi.org/10.5334/ijic.2449>
14
15
16
17

18
19 3 Lau JY, Wong EL, Chung RY, et al. Collaborate across silos: Perceived barriers to
20 integration of care for the elderly from the perspectives of service providers. *Int J Health*
21 *Plann Manage*. 2018 Apr 27. doi: 10.1002/hpm.2534.
22
23
24
25

26
27 4 SOU (2020:80) Äldreomsorgen under pandemin [Elder care during the pandemic]. Swedish.
28
29

30
31 5 Nedlund AC, Taghizadeh Larsson A. "To protect and to support: How citizenship and self-
32 determination are legally constructed and managed in practice for people living with dementia
33 in Sweden." *Dementia*. 2016;15(3): 343-357.
34
35
36
37

38
39 6 World Health Organization [WHO]. Continuity and coordination of care. A practice brief to
40 support implementation of the WHO Framework on integrated people-centred health services.
41 Geneva; WHO; 2018.
42
43
44
45

46
47 7 World Health Organization [WHO]. Integrated care for older people (ICOPE)
48 implementation framework: guidance for systems and services. Geneva; WHO; 2019.
49
50
51
52

53 8 Marcusson J, Blennow K, Skoog I, et al. Alzheimers sjukdom och andra kognitiva
54 sjukdomar. Stockholm: Liber; 2011.
55
56
57
58
59
60

9 World Health Organization [WHO]. World report on ageing and health. Switzerland: WHO; 2015.

10 World Health Organization [WHO]. Risk reduction of cognitive decline and dementia: WHO guidelines. Switzerland: WHO; 2019.

11 Christensen K, Doblhammer G, Rau R, et al. Ageing populations: the challenges ahead. *Lancet* (London, England), 2009;374(9696):1196–1208. [https://doi.org/10.1016/S0140-6736\(09\)61460-4](https://doi.org/10.1016/S0140-6736(09)61460-4)

12 Backhouse A, Richards DA, McCabe R, et al. Stakeholders perspectives on the key components of community-based interventions coordinating care in dementia: a qualitative systematic review. *BMC health services research*, 2017;17(1); 767. <https://doi.org/10.1186/s12913-017-2725-y>

13 Brodaty H, Thomson C, Thompson C, et al. Why caregivers of people with dementia and memory loss don't use services. *Int J Geriatr Psychiatry*. 2005;Jun;20(6):537-46. doi: 10.1002/gps.1322.

14 Røsvik J, Michelet M, Engedal K, et al. Interventions to enhance access to and utilization of formal community care services for home dwelling persons with dementia and their informal carers. A scoping review. *Aging Ment Health*. 2020 Feb;24(2):200-211. doi:10.1080/13607863.2018.1523876.

15 Tam-Tham H, Cepoiu-Martin M, Ronksley PE, et al. Dementia case management and risk of long-term care placement: a systematic review and meta-analysis. *Int J Geriatr Psychiatry*. 2013Sep;28(9):889-902. doi: 10.1002/gps.3906

16 Khanassov V, Vedel I. Family physician–case manager collaboration and needs of patients with dementia and their caregivers: a systematic mixed studies review. *Ann Fam Med*, 2016;14(2):166-177; DOI: <https://doi.org/10.1370/afm.1898>

17 Khanassov V, Vedel I, Pluye P. Barriers to implementation of case management for patients with dementia: a systematic mixed studies review. *Ann Fam Med*. 2014 Sep-Oct;12(5):456-65. doi: 10.1370/afm.1677.

18 Schiller C, Grünzig M, Heinrich S, et al. Case management for people with dementia living at home and their informal caregivers: A scoping review. *Health Soc Care Community*, 2021;1–21.

19 Saragih ID, Tonapa SI, Lin CJ, et al. Effects of case management intervention for people with dementia and their carers: A systematic review and meta-analysis of experimental studies. *Int J Nurs Stud*. 2021 Sep;121:104012. doi: 10.1016/j.ijnurstu.2021.104012.

20 Reilly S, Miranda-Castillo C, Malouf R, et al. Case management approaches to home support for people with dementia. *Cochrane Database Syst Rev*. 2015 Jan 5;1(1):CD008345. doi: 10.1002/14651858.CD008345.pub2.

21 Belle S, Burgio L, Burns R, et al. Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: a randomized, controlled trial. *Ann intern med* 2006;145(10):727-738.

22 Verkade P, van Meijel B, Brink C, et al. Delphi research exploring essential components and preconditions for case management in people with dementia. *BMC Geriatrics*, 2010;10(1);54.

- 23 Tricco AC, Lillie E, Zarin W, et al. A scoping review on the conduct and reporting of scoping reviews. *BMC Med Res Method*. 2016;16:15 DOI 10.1186/s12874-016-0116-4
- 24 Tricco AC, Lillie E, Zarin W, et al. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. *Ann Intern Med*; 2018;169(7):467-73.
- 25 Peters MDJ, Godfrey C, McInerney P, et al. Chapter 11: Scoping Reviews (2020 version). In: Aromataris E, Munn Z (Editors). *JBIM Manual for Evidence Synthesis*, JBI, 2020. Available from <https://synthesismanual.jbi.global>. <https://doi.org/10.46658/JBIMES-20-12>
- 26 Read, ST, Toye C, Wynaden D. The participation of people with dementia in the planning of their care and support: An integrative literature review. *Dementia*, 2020;19(3): 691-707. DOI: 10.1177/1471301218784806
- 27 Page M, McKensy J, Bossuyt P, et al., The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *Int J Surgery*. 2021;88.
- 28 Tomlin, G, Borgetto B. Research Pyramid: A new evidence-based practice model for occupational therapy. *Amer J Occup Ther*, 2011;65:189–196. doi: 10.5014/ajot.2011.000828
- 29 Ritchie J, Lewis J. Qualitative Research Practice: A Guide for Social Science Student and Researchers. London: Sage; 2003.
- 30 Olding M, McMillan S, Reeves S, et al. Patient and family involvement in adult critical and intensive care settings: a scoping review. *Health Expectation*. 2016;19: 1183-1202.

Appendix 1: Search strategy

Date searched: February 24, 2022

Alzheimer disease[MeSH Major Topic]) OR (Alzheimer disease[MeSH Terms])) OR
 (Alzheimer*[Title/Abstract])) OR (((Frontotemporal Lobar Degeneration[MeSH Major
 Topic]) OR (Frontotemporal Lobar Degeneration[MeSH Terms])) OR (Frontotemporal Lobar
 Degeneration[Title/Abstract])) OR (Frontotemporal dementia[MeSH Major Topic])) OR
 (Frontotemporal dementia[MeSH Terms])) OR (((Lewy Body Disease[MeSH Major Topic])
 OR (Lewy Body Disease[MeSH Terms])) OR (Lewy Body*[Title/Abstract])) OR (Lewy
 bodie*[Title/Abstract])) OR (((Vascular dementia[MeSH Major Topic]) OR (Vascular
 dementia[MeSH Terms])) OR (((dementia[MeSH Major Topic]) OR (Dementia[MeSH
 Terms])) OR (Dement*[Title/Abstract])) OR (Senile*[Title/Abstract])) AND
 (((((((((((health coord*[Title/Abstract]) OR (care coord*[Title/Abstract])) OR (care
 collab*[Title/Abstract])) OR (health collab*[Title/Abstract])) OR (health
 manage*[Title/Abstract])) OR (care manage*[Title/Abstract])) OR (Case
 Manage*[Title/Abstract])) OR (Case Management[MeSH Major Topic])) OR (Case
 Management[MeSH Terms]) OR (integrated care* [Title/Abstract])) OR (integrated health
 [Title/Abstract])) OR (comprehensive care [Title/Abstract])) OR (seamless care*
 [Title/Abstract])) OR (transmural care[Title/Abstract]))

Appendix 2: Data extraction table

No.	Study reference	Origin/country of origin	Aims/purposes	Methodology/ Design	Participants	Stakeholder	Intervention model	Key outcome/ key findings	Evidence grading

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.	
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.	
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.	
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.	
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.	
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.	
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.	
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	
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 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.	
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).	
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
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.	
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	
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.	
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	
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.	
Limitations	20	Discuss the limitations of the scoping review process.	
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.	
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.	

JB I = 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.

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

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

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

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med*. 2018;169:467–473. doi: 10.7326/M18-0850.



St. Michael's

Inspired Care.
Inspiring Science.

For peer review only - <http://bmjopen.bmj.com/site/about/guidelines.xhtml>