# 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

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### **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 Joanna Briggs Institute 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.

### INTRODUCTION

Problems concerning fragmentation 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<sup>1 2</sup> in terms of structural and organisational deficits in elder care systems, boundaries between various agencies and actors, and uncertainties regarding the division of responsibility between different

# STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The methodology of the scoping review will be reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews.
- ⇒ Several different databases—covering different scholarly disciplines of relevance for the aim of the scooping 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.

agencies as stipulated in laws and regulations.<sup>5</sup> 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 among 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 WHO, 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.' (p9)<sup>6</sup>. 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<sup>7</sup> 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 macrolevel (system level; eg, available services, accountability systems, financing health and care services, guidelines and regulations, national boards of directions), mesolevel (service level, eg, coordination of services delivered by multidisciplinary providers) and microlevel (person-centred goals; eg, 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 (ie, macro, meso, micro) and within the same agency or between different agencies. Collaboration and coordination are therefore important aspects to achieve integrated care among multiple care providers, within interdisciplinary teams or across care settings or sectors to improve patient's experience and outcomes of

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.<sup>8</sup> 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 careproviding 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. <sup>13</sup> 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. In a previous scoping review, Røsvik et al 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. A variety of professions (eg, 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 (eg, 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 (ie, agency representatives, service providers, care units, between and among 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 case management as a complex intervention to identify and cater for various needs among people with dementia<sup>16 18</sup> 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.<sup>20</sup> In addition, in a systematic review, Saragih et al<sup>19</sup> 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, that is, 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.<sup>22</sup> 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. 1218

Even though there is a legal requirement in many countries for different agencies and various professionals to collaborate and coordinate their activities,<sup>7</sup> 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 (ie, 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. <sup>23</sup> The findings of the scoping review will be finalised in April 2023.

### **Eligibility criteria**

The eligibility criteria for the present scoping review follow the PRIMSA-ScR<sup>24</sup> <sup>25</sup> and will be structured in regard to participants, concept and context. Furthermore, study characteristics (ie, 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<sup>26</sup> 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 (ie, 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. In this scoping review, different diagnoses of dementia, as described in International statistical classification of diseases and related health problems: tenth revision (ICD-10) and Diagnostic and statistical manual of mental disorders (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<sup>7</sup> description of integrated care, namely an 'approach to bringing together care professionals and providers to meet the needs of service users' (p. 9).<sup>6</sup> 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 predefined 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 macrolevel, mesolevel or microlevel 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 (ie, 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<sup>24</sup> 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<sup>25</sup> 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 (ie, 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. Online supplemental 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, PsycINFO, 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,<sup>27</sup> 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 A-CN. 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.<sup>27</sup>

# 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 A-CN. The data extraction will be recorded in a Microsoft Excel spreadsheet. A preliminary draft of the spreadsheet can be found in online supplemental appendix 2. The data subject for extraction has been inspired by the JBI manual<sup>25</sup> 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 (ie, 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. First, a summary of basic characteristics will be presented in tabular format and in running text. 25 Second, all included studies will be critically appraised using the Research Pyramid (ÅLR).<sup>28</sup> This will be done at an abstract level of the included studies and presented in a tabular format. According to the IBI 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.<sup>25</sup> Nonetheless, a critical appraisal based on the Research Pyramid<sup>28</sup> 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<sup>29</sup> 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<sup>30</sup> as scoping reviews usually do not synthesise the results of the included studies.<sup>2</sup> 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 subcategories) 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 among 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.

**Contributors** 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 A-CN have participated actively in the design of the methodology of the scoping review and in writing the protocol.

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#### REFERENCES

- 1 Bångsbo A, Dunér A, Dahlin-Ivanoff S, et al. Barriers for interorganisational collaboration: what matters for an integrated care programme? *Int J Integr Care* 2022;22:22:22.
- 2 Lyngsø AM, Godtfredsen NS, Frølich A. Interorganisational integration: healthcare professionals' perspectives on barriers and facilitators within the Danish healthcare system. *Int J Integr Care* 2016:16:4.
- 3 Lau JY-C, Wong EL-Y, 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 201810.1002/hpm.2534. [Epub ahead of print: 27 Apr 2018].
- 4 SOU. Äldreomsorgen under pandemin [Elder care during the pandemic]. Swedish, 2020: 80.
- 5 Nedlund A-C, 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;15:343–57.
- 6 World Health Organization (WHO). Continuity and coordination of care. In: 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 2009;374:1196–208.

- 2 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 Serv Res 2017;17:767.
- 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;20:537–46.
- 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;24:200–11.
- 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 2013;28:889–902.
- 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;14:166–77.
- 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;12:456–65.
- 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 2022;30:1–21.
- 19 Saragih ID, Tonapa SI, Lin C-J, 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 2021:121:104012.
- 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;1:CD008345.
- 21 Belle SH, 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;145:727–38.
- 22 Verkade P-J, van Meijel B, Brink C, et al. Delphi research exploring essential components and preconditions for case management in people with dementia. BMC Geriatr 2010;10:54.
- 23 Tricco AC, Lillie E, Zarin W, et al. A scoping review on the conduct and reporting of scoping reviews. BMC Med Res Methodol 2016;16:15.
- 24 Tricco AC, Lillie E, Zarin W, et al. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. Ann Intern Med 2018;169:467–73.
- 25 Peters MDJ, Godfrey C, McInerney P. Chapter 11: Scoping Reviews (2020 version). In: Aromataris E, Munn Z, eds. JBI manual for evidence synthesis. JBI, 2020. https://synthesismanual.jbi.global
- 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;19:691–707.
- 27 Page MJ, McKenzie JE, Bossuyt PM, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. Int J Surg 2021;88:105906.
- 28 Tomlin G, Borgetto B. Research pyramid: a new evidence-based practice model for occupational therapy. Am J Occup Ther 2011:65:189–96.
- 29 Ritchie J, Lewis J. Qualitative research practice: a guide for social science student and researchers. London: Sage, 2003.
- 30 Olding M, McMillan SE, Reeves S, et al. Patient and family involvement in adult critical and intensive care settings: a scoping review. Health Expect 2016;19:1183–202.