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Unmet social needs of community-living older adults with dementia: a scoping review

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ADMINISTRATIVE INFORMATION

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Review Stage at time of this submission - Piloting of the study selection process.

Conflicts of interest - None declared.

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Amendments - This protocol was registered with the International Platform of Registered Systematic Review and Meta-Analysis Protocols (INPLASY) on 20 December 2023 and was last updated on 20 December 2023.

INTRODUCTION

Review question / Objective The objective of this scoping review is to map the research evidence on unmet social needs of community-living older adults diagnosed with dementia. The questions are:

- 1) What are the unmet social needs of community-living older adults with dementia?
- 2) What unmet social needs community-living older adults with dementia experience along the different stages (severity) of dementia?

Background The World Health Organization's (WHO) Decade of Healthy Ageing (2021) defines 'healthy ageing' as 'the process of developing and maintaining the functional ability that enables well-being in older age'. Functional abilities encompass the capacity to meet one's basic needs; learn, grow, and make decisions; maintain mobility;

contribute to society; and to build and maintain relationships. This definition puts social needs as an integral aspect of healthy ageing, encompassing the needs for social and leisure activities, daytime activities, community life activities, engagement in meaningful occupation, social companionship and interpersonal relationships (Chilvers et al. 2010; Turcotte et al. 2015; Carvacho et al. 2021). As people age, the ability to build and maintain social interactions diminishes due to various factors. Retirement signals decreased daily contact with co-workers, and physical frailty and health problems associated with ageing contributes to reduced mobility (Costa et al. 2022). The loss of relatives, spouses and close friends further contributes to a reduction in social interactions, mobility, and opportunities to form relationships (Van Aerschot et al. 2022; Costa et al. 2022).

Literature suggests that older adults with dementia tend to report more social unmet needs than those without cognitive impairment (Carvacho et al. 2021). Dementia, a neurocognitive disorder affecting more than 55 million people worldwide, poses several challenges to social interaction and leisure participation to both people with dementia and caregivers (Grand et al. 2011). It is a medical condition characterized by a decline in cognitive functioning with impairments in areas such as memory, language, and social cognition (WHO, 2023). Behavioral and psychological symptoms in dementia (BPSD) can further impact on social engagement, affecting the dyad's psychosocial health (Feast et al. 2016; Warren. A, 2022). During the early stages of dementia, individuals can take part in community or social activities without help and may appear unimpaired to those who do not know them well (WHO 2023, ICD-11 for Mortality and Morbidity Statistics Dementia). In the middle stage, signs and symptoms progress and become increasingly restricting (WHO 2019, Dementia Key facts). In the late stages, affected individuals may have complete dependence, inactivity, serious memory disturbances and physical signs.

Studies focusing on community-living older adults with dementia highlight numerous unmet social needs, particularly related to daytime activities (e.g., social, work, leisure, learning activities), receiving company (e.g., social contact, contact with friends), and receiving help with psychological distress (e.g., agitation, needs for sympathy and support) (Black et al. 2013; Miranda-Castillo et al. 2010; Mazurek et al. 2019; Black et al. 2019). Recognizing and addressing the unmet social needs of community-living older adults with dementia is crucial, as they are associated with a lower health-related quality of life and more symptoms of depression (Miranda-Castillo et al. 2010; Black et al. 2013; Janssen et al. 2018). Enabling older adults with dementia to be independent in their homes has been a priority among many governments as they recognize its positive impact on their physical and mental well-being, along with the cost-effectiveness compared to institutionalization (Alzheimer Europe, 2008). Research data has shown that compared to institutionalization, living at home is associated with higher levels of activity, more social contact, less use of psychotropic medications and higher quality of life (Olsen et al. 2016).

Rationale Through a preliminary literature search, a scoping review (Morrisby et al. 2017) and a meta-analysis (Curnow et al. 2021) were found investigating the met and unmet global needs of older adults with dementia and their caregivers. Needs in different areas were reported, namely information, self-care, and peer support. Both

studies (Morrisby et al. 2017; Curnow et al. 2021) report the prevalence of needs across different domains, without focusing on social needs. A preliminary search of PubMed, INPLASY, the Cochrane Database of Systematic Reviews and JBI Evidence Synthesis was conducted, and no current or underway systematic reviews or scoping reviews on social needs for community-living older adults with dementia were identified. There is currently a gap in the understanding of the met and unmet needs of older adults with dementia, specifically to the social domains and among those living in the community. The current literature also does not provide clear insights on whether variations exist in met and unmet social needs across the progression of dementia.

Scoping reviews can be used to map and summarize the evidence and identify knowledge gaps (Peters et al. 2020). The scoping review is an adequate method for exploring the literature, allowing for different study methodologies. The knowledge from the review is expected to enhance the overall understanding of unmet social needs among community-living older adults with dementia across the disease progression.

METHODS

Strategy of data synthesis For this review, the PRISMA- ScR guidelines will be adopted to help standardise reporting (Tricco et al. 2018). The following electronic databases will be searched: PubMed, Scopus, Web of Science and Academic Search Complete. An initial limited search of Pubmed will be undertaken to identify articles on the topic. The text words contained in the titles and abstracts of relevant articles, and the keywords used to describe the articles will be used to develop a full search strategy for the selected databases. The full search strategy for Pubmed is provided in this scoping review protocol for reference (see Table 1).

This scoping review will include peer-reviewed articles encompassing any types of study designs. The reference list of all included sources of evidence will be screened for additional studies. Systematic reviews, meta-analyses, unpublished studies, and grey literature sources (e.g., reports and conference abstracts) will be excluded. This scoping review adopts a focus on the peer-reviewed literature as the consistency in reporting enhances the reliability and comparability of the information gathered (Snedeker et al. 2010).

This scoping review will include studies published after year 2000. While the term 'unmet needs' began to appear as early as the 1900s, the type of needs reported were related to activities of daily living, nursing needs and service needs (Jackson

et al. 1991; Siegel et al. 1991). The early definitions of 'healthy ageing' by the WHO focused on primary ageing without pathologies (Paúl et al. 2012). However, in the XXI century, a more comprehensive concept of active ageing emerged, encompassing psychological, social, and economic aspects beyond health indicators (WHO, 2002; Paúl et al. 2012). To align with the current accepted concepts of ageing, this review will include studies from the year 2000 onwards. Additionally, a screening of the reference list of a recent scoping review on 'unmet care needs of older people' was performed (Kalánková et al. 2021). Five papers that met the inclusion criteria based on titles and abstracts will be added to the list of full texts for further screening (Gaugler et al. 2005; Raivio et al. 2007; Cohen-Mansfield et al. 2015; Mazurek et al. 2019; Black et al. 2019). Notably, no relevant papers from before the year 2000 were identified.

Table 1: Search strategy for PubMed

	Query
#1	"older people" OR elderly OR "old person" OR "older adults"
#2	dementia OR Alzheimer OR "Neurocognitive disorder"
#3	"social needs" OR leisure OR occupation OR interact* OR activit*
#4	home OR community OR "community-living"
#5	#1 AND #2 AND #3 AND #4 Limits: - Abs/ title - After year 2000 - Only Review, Clinical Trial, Randomized Controlled Trial - Only English, Portuguese, Chinese language

Eligibility criteria The inclusion criteria were defined following JBI's recommendations for scoping reviews (Peters et al. 2020) (Table 2). Population: older adults with dementia, of all dementia types and stages; Concept: unmet social needs; Context: community-living.

Table 2 Inclusion and exclusion criteria

	Inclusion criteria	Exclusion criteria
Population	<ul style="list-style-type: none"> Older adults (≥65 years old) diagnosed with dementia. 	<ul style="list-style-type: none"> Other age groups Only caregivers
Concept	<ul style="list-style-type: none"> Met and/or unmet social needs, i.e., social activities, daytime activities, community life activities, engagement in meaningful occupation, social companionship, and interpersonal relationships. 	<ul style="list-style-type: none"> Other needs Needs of caregivers only
Context	<ul style="list-style-type: none"> Community-living 	<ul style="list-style-type: none"> Live in nursing care and residential homes, inpatient settings, or hospitals
Other	<ul style="list-style-type: none"> Peer-reviewed articles Any type of study design Published after year 2000 	<ul style="list-style-type: none"> Systematic reviews or meta-analyses Unpublished studies and grey literature (e.g., reports and conference abstracts, books, documents)

Source of evidence screening and selection All the records identified through database searching will be retrieved and stored into Zotero and duplicates removed. Then, the citations will be imported into Rayyan QCRI (Qatar Computing Research Institute (Data Analytics), Doha, Qatar) for screening. The first reviewer will conduct title and abstract screening of all articles while the second reviewer will independently screen 20% of the articles (Mak & Thomas, 2022). Both reviewers will discuss any disagreements, and a consensus will be reached. A third reviewer will appraise the findings when there is a disagreement. If a study's abstract is unclear or its relevance is uncertain, it will be considered for full-text screening. All potentially eligible studies will be retrieved in full-text and be assessed in detail against the inclusion criteria. Next, the first reviewer will conduct full-text screening while the second reviewer independently screens 50% of the included articles (Mak & Thomas, 2022). Similarly, both reviewers will discuss any agreements until a consensus is reached. A third reviewer will appraise the findings when there is a disagreement. Full-text will be excluded if they did not meet the inclusion criteria. Lastly, the reference list of all included articles identified within the original search will be checked for additional relevant citations. If the full-text version of an article is inaccessible, the original authors will be contacted. The results of the search and the study inclusion process will be reported in full in the final scoping review and presented in a Preferred Reporting Items for Systematic Reviews and Meta-analyses extension for scoping review (PRISMA-ScR) flow diagram (Tricco et al. 2018).

Data management Data will be extracted from papers included in the scoping review using a data extraction tool developed by the reviewers. The data extracted will include specific details about the author, year of publication, country of origin, study aims, methods, participants, and key findings relevant to the review questions. A draft extraction form is modified from the 'JBI template source of evidence details, characteristics and results extraction instrument' (Aromataris & Munn, 2020). The draft data extraction tool will be modified and revised as necessary during the process of extracting data from each included evidence source. Modifications will be detailed. This data extraction form will be reviewed and pre-tested by the reviewers to ensure consistency in data extraction and that all the necessary information is captured from each study. In the case of missing data, the study authors will be contacted for additional data information. Each reviewer will then independently extract data from the included studies, and comparisons will be

made afterwards. Any disagreements that arise between the reviewers will be resolved through discussion. Finally, the data will be combined into a single Microsoft Excel spreadsheet.

Reporting results / Analysis of the evidence

After all the data from the included studies have been tabulated in the main data extraction excel sheet, the data will be categorised and summarised. For quantitative results, we will report the number and proportion of studies reporting each type of unmet social need. For qualitative results, an initial thematic framework will be developed based on the main outcomes identified from a preliminary reading of the included studies. One researcher will assign each study to a primary theme within this framework. As coding progresses, new themes will be incorporated into the framework and previously coded studies will be reassessed within the updated framework. Once a final framework is obtained, primary themes will be assigned to each study by one researcher and will be validated by a second researcher. Discrepancies will be discussed and resolved. Where appropriate, studies will be assigned primary and secondary themes.

Presentation of the results The findings of the study will be presented according to the PRISMA-ScR checklist. A PRISMA flow chart will be used to present the methodological process in detail. For ease of presentation, results of included studies will be grouped according to the main themes. Each study will also be categorised according to the type of unmet social need expressed, population (type and stage of dementia) and method of assessment used to evaluate the social need. Gaps in literature will be discussed, and areas for further research will be identified.

Language restriction Only studies in English, Portuguese, Chinese will be included.

Country(ies) involved Portugal.

Keywords Dementia, Neurocognitive disorder, Unmet needs, Social, Participation, Community-living, Older adults.

Contributions of each author

Author 1 - Sunny Tan - Conceptualised the review approach, developed the review questions and the review design, and initiated the first draft of this manuscript.

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Author 2 - Liliana Sousa - Contributed to the funding acquisition, conceptualisation, research

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