

BMJ Open Protocol for a scoping review on information needs and information-seeking behaviour of people with dementia and their non-professional caregivers

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ABSTRACT

Background Dementia is a debilitating disease that can lead to major changes in a patient's behaviour and function. It is important to educate both patients with dementia and their non-professional caregivers about the disease. Yet, currently available sources do not seem to be effective for patients and caregivers, who report a need for more information and guidance. A systematic identification of the patients' and caregivers' needs for information and information-seeking behaviour is needed to create information resources that are relevant and beneficial to the target population.

Objectives This is a protocol for a scoping review aimed at gathering knowledge on the information needs and information-seeking behaviour of patients with dementia and their non-professional caregivers. Our aim was also to provide recommendations for development of future dementia information resources.

Methods The study will commence in November 2018. Both quantitative and qualitative studies on the information needs of patients with dementia or caregivers will be examined using Arksey and O'Malley's methodological framework for scoping studies. A comprehensive literature search will be conducted in electronic databases and grey literature sources. We will also screen reference lists of included studies and related systematic reviews for additional eligible studies. Two authors will perform screening of citations for eligibility and independently extract data from the included studies in parallel. Any discrepancies will be resolved through discussion. The findings will be presented through a narrative synthesis and reported in line with Preferred Reporting Items for Systematic Reviews and Meta-Analyses reporting guidelines.

Ethics and dissemination In this review, all included data will originate from published literature. Ethics approval is therefore not a requirement. We will present our findings at relevant conferences and will submit them for publication in peer-reviewed journals.

BACKGROUND

The world's population is steadily ageing, with a corresponding increase in the prevalence of dementia and its disease burden.^{1 2}

Strengths and limitations of this study

- In this scoping review, we will perform a comprehensive search of electronic databases and grey literature sources to identify up-to-date evidence on information needs and information-seeking behaviour of patients with dementia and their informal caregivers.
- We will seek to identify evidence on information needs and information-seeking behaviour of both patients with dementia and their caregivers.
- As this is a scoping review, a formal quality and risk of bias assessment of the included literature will not be performed.
- This review will include studies published in English.

It is estimated that today 50 million people worldwide have dementia, and this number is set to increase to 131.5 million by 2050.^{3 4} Dementia causes cognitive decline, memory impairment and behavioural change.³ As the disease progresses, patients lose the ability to care for themselves and perform activities of daily living, for example, bathing, doing household chores and cooking. In later stages, many patients with dementia require full-time caregivers, most of whom are their own family members.⁵ There is no cure, with current treatment primarily aimed at slowing progression and managing symptoms.⁶

Existing systematic reviews on this topic involve only dementia caregivers, and most of them focus on service needs, not information needs.⁷⁻¹⁰ However, as with any other chronic disease, patient education and information provision are an important aspect in the long-term management of dementia. The debilitating nature of the disease results in most patients eventually requiring a permanent carer. As majority of caregivers for these patients are informal caregivers without prior

**Table 1** Inclusion and exclusion criteria

Inclusion criteria	<ul style="list-style-type: none"> ▶ Study population consisting of patients with dementia (including common dementia syndromes, namely, Alzheimer's disease, vascular dementia, presenile dementia, frontotemporal dementia syndromes and dementia with Lewy bodies) or current non-professional caregivers of these patients (eg, family members or neighbours). ▶ Study population involving patients at any stage of dementia. ▶ Studies focusing primarily on information needs or information-seeking behaviour of the target population. ▶ All primary studies, regardless of study design.
Exclusion criteria	<ul style="list-style-type: none"> ▶ Study population consisting of <ul style="list-style-type: none"> – Patients with conditions associated with dementia (eg, AIDS dementia complex, primary progressive aphasia, Creutzfeldt-Jakob syndrome, primary progressive non-fluent aphasia, Huntington disease and Kluver-Bucy syndrome). – Patients with cognitive decline or memory impairment, that is, not a result of dementia. – Patients with dementia and another condition (eg, dementia and Down's syndrome). ▶ Studies including only professional caregivers (eg, nurses, doctors and allied healthcare professionals). ▶ Studies involving patient or caregiver perspectives before the diagnosis of dementia. ▶ Studies examining the effect of a predetermined intervention. ▶ Studies focusing on general needs (eg, service needs and psychological needs) without specific mention of information needs. ▶ Secondary research studies.

education or training in dementia care, caregiver education is equally important to ensure continued quality care for the patient. Provision of information about the disease to both patients and caregivers will help them cope with the effect of the disease on their lives. This is reflected in current literature, which show that providing information to patients can lead to better outcomes, such as increased involvement in medical decision-making and improved patient compliance.^{11 12} Furthermore, with the proliferation of access to the internet, people are increasingly turning to the internet to seek out health information.^{13 14}

STUDY RATIONALE

Existing literature highlights that current interventions providing dementia information may not be effective for patients with dementia and caregivers, highlighting a need to delineate what these groups of people truly

require.¹⁰ A systematic review by Thompson *et al* states that there is a lack of impact from passive information provision interventions.¹⁰ The need for further information on how to deal with behavioural and psychological symptoms of dementia has also been highlighted, due to the challenges that caregivers face in managing these symptoms.¹⁵ Other than management of the varied needs of the patient through disease progression, caregivers also require information on legal and financial issues.¹⁶

To ensure the efficacy of information provided to these patients with dementia and caregivers, there is a need to design information provision strategies based on their needs. Hence, in order to improve current education strategies, the information needs of patients with dementia and caregivers, as well as the way they seek information, have to be systematically identified.

STUDY OBJECTIVES

The objectives of this scoping review were to understand the information needs and information-seeking behaviour of people with dementia and of their caregivers, and to provide recommendations for the future development of dementia information resources and research. We chose to use the scoping review model as our aim was to provide a broad overview of all possible information needs and information-seeking behaviour within the literature, and to identify gaps present in information needs and information provision interventions. The purpose of this review was not to answer a specific and focused review question, or to critically appraise the current evidence; hence, we felt that a scoping review was more suitable for our objective. In this scoping review, perspectives of all non-professional caregivers and the patients themselves will be explored, with no limits imposed on the study type or publication date to ensure a comprehensive picture regarding the information needs and information-seeking behaviour of our target population.

METHODS AND ANALYSIS

Protocol design

In this scoping review, we developed methods following Arksey and O'Malley's scoping study methodological framework.¹⁷ This comprises five stages: (1) identifying the research question; (2) identifying relevant studies; (3) study selection; (4) charting the data; and (v) collating, summarising and reporting the results. Due to resource constraints, we did not include the consultation stage of the scoping methodology that is mentioned in Levac *et al's* scoping study methodological framework.¹⁸ Thus we used Arksey and O'Malley's approach instead.

Stage 1: identifying the research question

Through consultation and iterative discussion with the research team, the main review question was developed as 'What are the information needs and information-seeking behaviour of patients with dementia and their

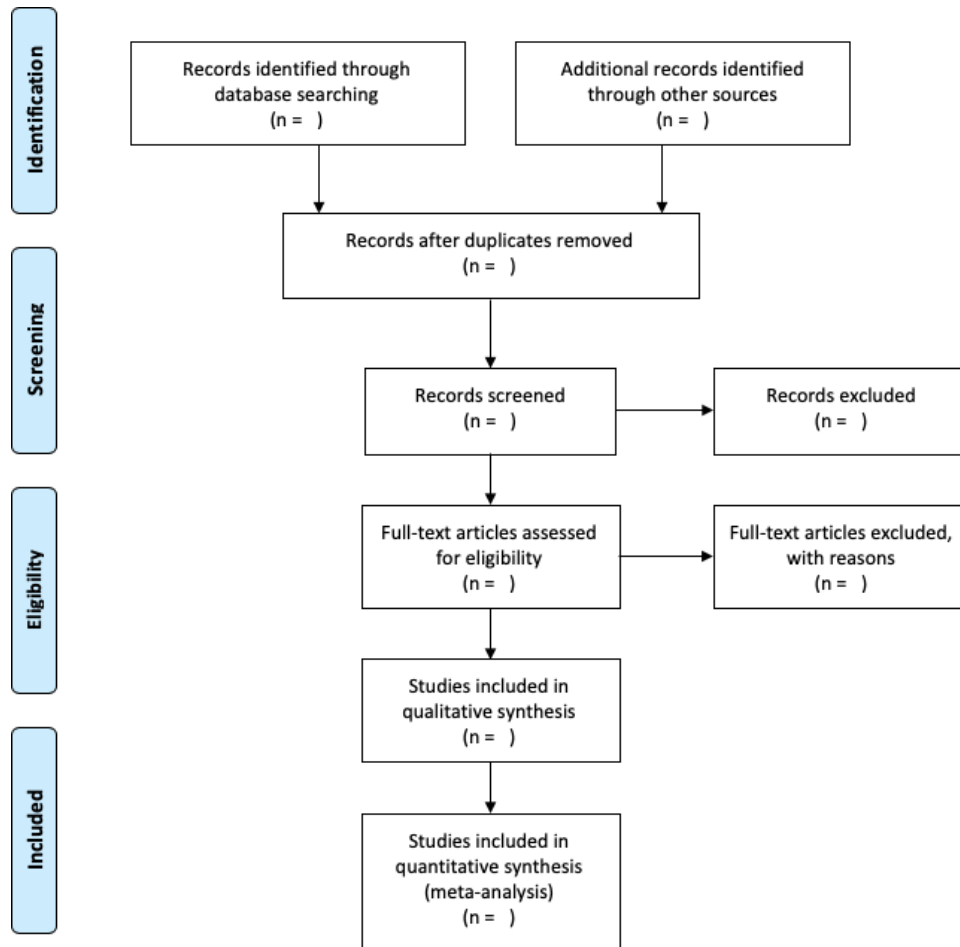


Figure 1 Flowchart of the study selection process as outlined by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines.

non-professional caregivers?’ For the purposes of this review, we defined information needs as resources desired by individuals to fulfil a gap in their knowledge, and we defined information-seeking behaviour as how and where information is obtained and used thereafter.

Stage 2: identifying relevant studies (search strategy and inclusion/exclusion criteria)

Using relevant keywords based on our research question and established eligibility criteria, we developed a pertinent search strategy (online supplementary appendix 1). The search strategy was developed with input from librarians experienced in this field. We will adapt the same strategy for use to search for papers on multiple online databases, namely, PubMed, MEDLINE, Embase, PsycINFO and CINAHL. We chose these databases as they contain more medical information. We will also search the reference lists of included studies and any relevant systematic reviews to ensure that relevant articles are not missed out. A search of grey literature, including various sites such as OpenGrey, Google, Google Scholar and OpenDOAR, will also be performed. For the search performed on Google and Google Scholar, we plan to use only the first 10 pages of search results in order to collect the most relevant results while ensuring that the search

remains practical.^{19 20} Only studies that are available in English language will be included for this study. We decided to include only studies in English due to limited resources that do not allow for screening and translation of studies in other languages. We will import the results into EndNote X8.2 (Thomson and Reuters 2018), a reference managing software.

Studies will be excluded if they focus on patients with dementia and another condition, for example, dementia and Down’s syndrome. We will exclude these studies as the presence of other medical conditions may affect patient demographics (they may develop dementia at a younger age), and the information needs in this population will be more specific and unique to each condition. A full list of inclusion and exclusion criteria is shown in table 1.

Stage 3: study selection

After obtaining all the citations, two reviewers will independently screen titles and abstracts of all the studies. The studies will be screened independently by two reviewers against the specified inclusion and exclusion criteria. Disagreements between reviewers will be resolved by discussion. Studies that are not relevant will be discarded and the remaining studies will then undergo full-text review. Similarly, the full text of these articles will

be screened independently by two reviewers to confirm relevance to this scoping study, and any discrepancies will be discussed and resolved at the end of the full-text screening. In cases where the two reviewers cannot come to a decision about a study, a third reviewer will act as the arbiter. For studies with missing or incomplete data, we will attempt to contact the authors for the relevant information. [Figure 1](#) depicts this process.

Stage 4: charting the data

After the screening process is completed, we will formulate a data charting form using Microsoft Excel to gather information from the included studies. Data will be extracted on author; year of publication; population demographics; relationship of carer to patient; type, severity and duration since dementia diagnosis; duration of caregiving; association with professional dementia services; types of information-seeking behaviour; current and wanted sources of information; and information needs. Piloting of the data extraction form will be carried out to ensure that relevant information is extracted from the studies. After the data charting form is finalised, it will be used to extract data from all the included studies. Data extraction is an iterative process and further amendments may be made in the event that additional important data are identified. Disagreements will be settled through discussion between the two authors, and a third reviewer will act as arbiter. We will contact the study authors for any missing or incomplete information.

Stage 5: collating, summarising and reporting the results

We will provide a summary of the included studies, including the overall number of studies, study design and data collection methods, types of participants, the caregiver's relationship with the patient, duration of caregiving, educational level of the caregiver and general aim of the study. Information needs will be organised into emerging themes relating to information needs and information-seeking behaviour. We will perform a narrative synthesis of the findings, and no qualitative analysis software will be used. This information will be presented using various diagrams, charts and figures. We will also identify any relationship between population characteristics and information needs or information-seeking behaviour, for example, potential association between the severity of dementia and the type of information needs. We will report the findings in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses: extension for Scoping Reviews.²¹ Further recommendations and plans for consultation will be made based on our findings.

Patient and public involvement

Patients and the public were not involved.

Contributors LTC conceived the idea for this study. STA, AS and BMK wrote the manuscript. LTC revised the manuscript critically.

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Competing interests None declared.

Patient consent for publication Not required.

Ethics approval Future disseminations related to this work will include the publication of the results in a peer-reviewed journal and presentations at conferences.

Provenance and peer review Not commissioned; externally peer reviewed.

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