Information needs and information seeking behaviour of dementia patients and their caregivers: a scoping review

Aijia Soong  
Lee Kong Chian School of Medicine

Shu Ting Au  
Lee Kong Chian School of Medicine

Bhone Myint Kyaw  
Lee Kong Chian School of Medicine

Yin Leng Theng  
Nanyang Technological University Wee Kim Wee School of Communication and Information

Lorainne Tudor Car  (lorainne.tudor.car@ntu.edu.sg)
https://orcid.org/0000-0001-8414-7664

Research article

Keywords: information needs, dementia, informal caregivers, information seeking behaviour, review

Posted Date: October 11th, 2019

DOI: https://doi.org/10.21203/rs.2.15434/v1

License: This work is licensed under a Creative Commons Attribution 4.0 International License.  Read Full License

Version of Record: A version of this preprint was published on February 14th, 2020. See the published version at https://doi.org/10.1186/s12877-020-1454-y.
Abstract

Background Patients with dementia often require full-time caregivers especially in the later stages of their condition. Patients and caregivers’ access to reliable information on dementia is essential as it may have an important impact on patient care and quality of life. This study aims to provide an overview of the information needs and information seeking behaviour of dementia patients and their caregivers.

Methods We conducted a scoping review of the literature and searched four electronic databases for eligible studies published up to August 2018. Two reviewers independently screened studies and extracted data. Information needs were classified according to emerging themes in the literature, and information seeking behaviour was categorized using Wilson’s model of information behaviour.

Results Twenty studies with a total of 4,140 participants, were included in this review. Reported information needs focused on: (i) disease; (ii) patient care provision; (iii) healthcare services; and (iv) caregiver self-care. The most commonly reported information need was on healthcare service-related information. Characteristics found to influence information needs were the severity of dementia as well as patient and caregiver status. Dementia patients and caregivers mainly displayed active searching information seeking behaviour and preferred using electronic sources to obtain health information.

Conclusion Current dementia information sources available in English are extensive in the information they offer, but more emphasis needs to be placed on healthcare service-related information. All studies originated from high income countries and focused on information needs of caregiver only. The only variable found to significantly influence information needs was severity of dementia condition. The information needs identified in this review can be used to inform development and design of future dementia resources for patients and their caregivers.

Introduction

The world’s population is steadily ageing, with a corresponding increase in the prevalence of dementia and its disease burden (1, 2). There are approximately 50 million people living with dementia worldwide, with this estimate set to rise to 152 million by 2050 (3). Dementia prevalence varies by geographic regions, with East Asia being the region with the largest number of people living with dementia, followed by Western Europe, South Asia and North America (1). The cost of dementia patient care is limited not just to financial burden, estimated at US$818 billion globally in 2015, but also extends to the caregiver’s physical, psychological and social strain (4, 5). As dementia progresses, patients lose the ability to care for themselves and independently perform activities of daily living (ADLs) such as bathing, doing household chores, and cooking. Many dementia patients would thus require full-time caregivers in the advanced stages of the disease, many of whom are their family members providing informal care (4).

Existing literature has shown that providing information to patients and their caregivers can lead to better outcomes such as improved patient compliance and increased involvement in medical decision-making (6, 7). With the constant innovations in technology, patients and caregivers are able to easily obtain the information they require from different sources such as mass media and the Internet (8, 9). Despite the increased access to information sources, interventions focused on information provision have not shown much efficacy (10) in meeting the information needs of patients and caregivers, implying that there could be other factors contributing to this inefficacy. In order to improve upon current strategies for dementia education, the information needs and information seeking behaviour of these groups of people have to be identified.

Existing reviews mostly focus on caregivers, their needs in general, or interventions to address caregiver needs, or have been undertaken more than 10 years ago (10-12). In this review, we aim to provide a broad scope of the current evidence by including perspectives of both patients and caregivers, without any restrictions on publication date, to summarise and identify the information needs and information seeking behaviour of dementia patients and their informal caregivers. Correspondingly, we performed a scoping review with the objectives to identify information needs and information seeking behaviours of patients with dementia and their caregivers and; examine whether, and to what extent information needs and behaviours are affected by variables such as participants’ socio-demographic or diseases-related characteristics.

Methods

Study Selection

This scoping review was undertaken in line with Levac’s framework for scoping studies (13) and reported according to Tricco and colleagues’ PRISMA extension for scoping reviews (14). We included all primary studies that investigated the information needs and information seeking behaviour of patients with dementia (irrespective of their stage of dementia) or their current non-professional caregivers. For the purpose of this review, we defined dementia as common types of dementia that include Alzheimer’s disease (AD), vascular dementia, frontotemporal dementia (FTD) and Lewy Body dementia (LBD). Studies were also considered eligible for our review if the information needs or information seeking behaviour was based on the first-hand perspective of the patients with dementia or their caregiver. We defined information needs as the need for new information, the need to confirm known information or the need to clarify
known information (15). We defined information seeking behaviour as “the purposive seeking of information as a consequence of a need to satisfy some goal”, following the definition by Wilson (16). We only included studies in English.

We excluded studies that included patients with certain diagnoses (i.e. AIDS dementia complex, primary progressive aphasia, Creutzfeldt-Jakob syndrome, primary progressive non-fluent aphasia, Huntington disease, Kluver-Bucy syndrome), with comorbidities (e.g. dementia and Down’s syndrome), as the information needs of these patients and their caregivers may differ from those with more common dementia syndromes. We excluded studies that included patients without a definitive diagnosis of dementia, and caregivers of these patients. We excluded studies that explored the information needs of healthcare professionals as well as those focusing on general needs (such as service needs, psychological needs etc.) without mention of informational needs. We excluded studies that involved the evaluation of interventions for dementia patients and caregivers.

Data sources, collection, analysis

A comprehensive search of the literature was conducted across the following databases: Medline (Ovid), Embase (Ovid), PsycINFO (Ebsco) and CINAHL (Ebsco). We searched the databases in August 2018 for relevant studies. The search terms within our search strategy included: information seeking behaviour, help seeking behaviour, needs assessment, health service needs, information needs, caregivers, spouse caregivers, family caregivers, dementia and Alzheimer’s disease. We searched reference lists of related systematic reviews to ensure that relevant articles were not omitted. A search of grey literature, including various sites such as OpenGrey, Google and openDOAR was also performed (See Appendix 1).

The search results were imported into EndNote X8.2 (Thomson and Reuters 2018) to form a single combined library. After duplicates were removed, two reviewers independently screened the collated titles and abstracts. The full texts of potential studies were retrieved and screened for their eligibility. Disagreements between the reviewers were resolved through discussion. The two reviewers independently extracted data using a data extraction form. Data for each study was extracted as follows:

- Study reference (author, year of publication, country where study was conducted, study design, study duration, study aims)
- Demographics of study population (number of participants, gender, age range, caregiver’s relationship to patient with dementia, type/severity/duration of dementia, duration of caregiving, income and occupation, education level of caregiver, association with formal dementia care services)
- Types of information seeking behaviour
- Data measurement (data collection procedure, instrument used)
- Information needs identified
- Information sources (current, preferred sources of information)
- Other needs as specified by the patient and/or caregiver

Inter-rater agreement between the two reviewers was calculated using Cohen’s kappa, and good agreement was determined to be achieved (kappa = 0.80) between the two reviewers. Discrepancies in the extracted data were resolved through discussion between the two reviewers. A third reviewer acted as a mediator where differences could not be resolved. Study authors were contacted where information was missing or incomplete.

No quality assessment was performed on the studies in this review, as the main aim of this scoping review was not to emphasise methodological inadequacies within the studies but to present a broad scope of the existing literature on the information needs and information seeking behaviour of patients with dementia and their caregivers.

Data synthesis and analysis

We performed a thematic analysis and categorised the data according to the emerging themes in the included studies. This was done independently by two reviewers in parallel. Discrepancies in thematic analysis were discussed between the study authors. Categories were developed using a ‘bottom-up’ approach, and were refined throughout the review process. Within each category of information need mentioned, we listed the reported information needs according to frequency mentioned. Information needs were sorted into four main themes: dementia-specific information, patient care-related information, service information and caregiver self-care related information. We evaluated the frequency of information needs and other needs by calculating the percentage of studies that were included in each information need contributing to the main information theme. The percentages for each theme was calculated upon 100%. We sought to evaluate if variables such as sociodemographic characteristics of the population and dementia severity influenced information needs and information seeking behaviour and to what extent.

We identified information seeking behaviour in the studies through patients’ and/or caregivers’ information sources, and their actions as specified in the article. For example, if a caregiver stated they often turned to their family doctor for more information on dementia, we would classify that as ‘active searching’ behaviour. Information seeking behaviour was grouped according to the four categories specified in Wilson’s model of information behaviour: active searching, passive searching, ongoing searching and passive attention (17). The four categories were defined as follows: Active searching was defined as the individual actively seeking out information. Passive searching was defined as “the acquisition of information that happens to be relevant to the individual”. Ongoing searching is “where active searching has already established the basic framework of knowledge, but where occasional continuing search is carried out to update or expand one’s framework”. Passive attention is where “information acquisition may take place without intentional seeking” (18). We selected Wilson’s model over other models of information behaviour as it offered a broad summary of the context of the information need of the seeker, the type of searching employed and the information sources utilised, and was not focused on the information seeking process. For current and preferred sources of information, the sources mentioned by studies in the literature were listed according to the frequency mentioned.
Our scoping review aimed to provide an outline of the information needs of patients with dementia and their informal caregivers, and we did not conduct further statistical analyses to investigate the relationship between sociodemographic variables and information needs or preferences.

Results

We identified a total of 2,447 abstracts in our preliminary search. After duplicates were removed, we screened 1,848 articles and eventually included 20 studies in this scoping study (Figure 1). After screening for titles and abstracts, we retrieved the full texts for 38 articles that explored the information needs or information seeking behaviour of patients with dementia and their caregivers. From these 38 articles, we excluded seven studies that did not meet our inclusion criteria. 20 studies from 21 reports, were eventually included in this review (Figure 1).

Figure 1: Study flow diagram

The 20 studies comprised of ten cross-sectional studies, eight qualitative studies, and two mixed methods studies with 4,140 participants (Appendix 2). One of the cross-sectional studies was reported twice. All studies were presented in English and published between 2002 and 2018. Four studies examined both caregiver and patient perspectives while the rest examined only the caregiver's. With the exception of four studies that did not report caregiver-patient relationship, the majority of the caregivers were the spouses or children of the patient. All studies were from high income countries, with eight studies from the USA.

Sample sizes ranged from 9 to 1181, apart from one study where sample size could not be determined due to study methodology. Majority of caregivers were female and had mean ages between 55 to 70 years. Mean ages of the patients was between 70 to 90 years. Education level of participants was stated in eleven studies, where most of the participants had completed at least high school education.

Of the types of dementia specified in this review, 35% of studies included dementia (19-25), 20% of studies included LBD (22, 25-27), 15% of studies included AD and other non-specific forms of dementia (19, 22, 25). However, 45% of studies did not specify the type of dementia (28-36). All 20 studies identified information needs irrespective of dementia types, however information seeking behaviour was only reported in 11 studies. Four studies further illustrated barriers to information needs and information seeking behaviour which included: lack of access, time, energy, knowledge to interpret or search for information and denial of the condition (19-21, 28)

Information needs

We identified four main themes in relation to information needs, with a total of 39 reported information needs. The four information themes were disease-specific information, healthcare service-related information, patient care provision, and caregiver self-care. Information related to healthcare services was the most commonly identified theme, while patient care provision represented the category with the most diverse number of information needs.

Disease-specific information

The three most commonly mentioned needs related to dementia were general information on dementia (10 studies, 62.5%), dementia treatment (7 studies, 43.7%) and identification and understanding of dementia symptoms and behaviour (6 studies, 37.5%). Other information needs within this category also included dementia prognosis (6 studies, 37.5%), current dementia medication (5 studies, 31.2%), experimental drugs and clinical trials (4 studies, 25%), current research on dementia (3 studies, 18.7%) and genetic aspects of dementia (2 studies, 12.5%). The following information needs were mentioned only once (0.06%): negative impact of dementia on family and community, information specific to different stages of dementia, chance of recovery and memory skills (Table 2).

The need for information on “negative impact of dementia on family and community” was defined by Hirakawa as the physical and psychosocial burden on family and community (21). It was stated that this would help the caregivers prepare for and cope with the behavioural and psychological symptoms of dementia, as these symptoms worsen through the progression of the disease.

Patient Care Provision

Patient care provision was the category with the largest number of reported information needs, comprising 14 out of the 39 unique information needs (35.8%) identified in this review. Seven studies (53.8%) within this category indicated a need for information on how to provide general care. General care included patient hygiene, food and nutritional information and best attitudes to adopt in caring. Ways to deal with the patient's behaviour (6 studies, 46.1%) was the second most commonly mentioned information need, followed by safety issues (5 studies, 38.4%). Safety issues encompassed information on how to improve the safety of the patient's home environment, how to keep patient safe and how to recognise fall risks and poor mobility. Other reported information needs in this category were coping on with patient hallucinations (2 studies, 15.3%), navigation of communication difficulties (2 studies, 15.3%), activities for the patient (2 studies, 15.3%), first aid and medical information (2 studies, 15.3%). Additional seven information needs were retrieved from only one study and these were: conflict resolution, patient ethics, helpful experiences of other caregivers, when to transfer the patient to the hospital, dealing with family and friends, advocating for the patient, and emergency situations.

Healthcare Service-related

The top information need within this category was where and how to use services, and available help (14 studies, 93.3%). This was also the information need that was reported by the largest number of studies, among all identified needs. Services and help referred to facilities (e.g. geriatric hospitals and nursing homes), healthcare professionals skilled in dementia diagnosis and treatment, or support groups for caregivers. Other service-related information needs were financial help and services (5 studies, 33.3%), legal issues (4 studies, 26.6%), application for care programs (2 studies, 13.3%), and insurance (2 studies,
13.3%). As with the other main information themes, there were several information needs that were only stated once (0.07%). For service-related information, this included home help, when to transfer a patient to the hospital, and transportation options.

**Caregiver self-care**

Self-care for the caregiver was only mentioned by four studies. Two studies identified information needs for stress management (50%), while carer's pension entitlements, managing caregiver's emotions, and general caregiver self-care such as exercise, diet and medications were identified by one study each (25%). This information theme had the smallest number of contributing studies and reported information needs.

**Variables affecting information needs**

The severity of dementia and patient/caregiver status were the only variables found to influence information needs in this review.

**Information needs at various stages of dementia**

Caregivers of patients with mild dementia were more likely to look for disease-specific information, as compared to caregivers of patients with moderate to severe dementia. Both groups of caregivers required general information on dementia, identifying and understanding dementia and current dementia medication. However, those caring for patients with mild dementia also needed information on genetic aspects of the disease, experimental drugs and current research on dementia while those caring for patients with advanced dementia were primarily concerned about dementia prognosis (Table 3).

The severity of the patient's condition did not affect the number of patient care provision-related information needs. While both groups of caregivers had equal numbers of patient care information needs, the subcategories of information requested did not overlap. Caregivers of patients with mild dementia needed information on how to care for the patient, first aid and when to transfer a patient to the hospital. Caregivers of patients with moderate to severe dementia desired medical information, information on how to deal with patient’s behaviour and safety issues.

Carers of patients with moderate to severe dementia also needed more information on healthcare services. Both groups of carers required information on where and how to use available services, and how to apply for daycare programs. Caregivers of patients in more advanced stages of dementia indicated an additional need for information on financial help and services.

**Patient versus caregiver information needs**

Three studies investigated the needs of patient groups alongside their caregivers (25, 27, 38). However, two of these studies did not segregate the information needs of patients from caregivers, therefore we were unable to present any differences in information needs for these particular studies (25, 27).

The remaining study, that did segregate the information needs of patients and caregiver, showed that patients and caregivers had a large overlap in 80% of their information needs (38). The topics of shared interest included identifying and understanding dementia, experimental drugs and clinical trials, current dementia medication, communication difficulties and how to manage them, how to deal with patient's behaviour, and patient activities. These topics were equally distributed between disease-specific and patient care provision themes. The topics of interest specific to the caregivers were genetic aspects of the disease, and how to deal with family and friends. On the other hand, the topics of interest unique to patients were clinical trials and where to find support groups. Overall, caregivers were more interested in topics specific to dementia, while patients were more concerned about service-related topics.

**Information Seeking Behaviour**

We classified information seeking behaviour into four categories, following Wilson's model of information behaviour (17). The four categories were passive attention, passive searching, active searching and ongoing searching. Information seeking behaviour was illustrated in 12 out of 20 studies (20-22, 25-28, 30-32, 35, 38). Ten studies reported active searching behaviour (20, 22, 25, 26, 28, 30-32, 35, 38) and four studies showed passive attention behaviour (21, 25, 27, 35). Ongoing searching and passive searching behaviour were indicated correspondingly in one study (21, 28). Four studies gave examples of two types of information seeking behaviour (21, 25, 28, 35). Two of these studies feature contrasting information searching behaviours of active searching and passive attention (25, 35). The other two studies had similar types of information seeking behaviours and were only active (active searching, ongoing searching) (28) or passive behaviours (passive attention, passive searching) (21).

Information seeking behaviour was mainly surmised from current information sources stated within the studies. These sources for patients and/or their caregivers were stated in 14 studies (19-22, 25, 27, 28, 30-33, 35, 36, 38). Of these 14 studies, six studies also mentioned desired information sources (22, 27, 28, 30, 33, 35). Two studies mentioned the preferred sources of caregivers without reference to their current information sources (26, 34). The most utilised source of information was the Internet (e.g. websites and forums) (10 studies, 71.4%), followed by healthcare professionals (7 studies, 50%), and family and friends (6 studies, 42.8%). Service employees (bank employees, clergy) were also approached for information, however this was the least common source of information as it was mentioned in one study (20, 36). Other sources of information utilised include the Alzheimer's Association, written information sources (e.g. magazines, leaflets and books), electronic sources (e.g. email, smartphone apps, videos), support groups, care centres, social workers, other family caregivers, and volunteer groups (Table 4).

**Figure 2. Percentage of Studies indicating Current and Preferred Information Sources**

The Internet was indicated as both the most highly utilised source of information and the most desired source of information for patients and caregivers. Most of the participants used Internet by browsing websites and forums to look for information. However, what patients and caregivers desired when using the
Internet were more specific online resources, such as a website with frequently asked questions, how-to videos for patient care and dementia and service-related information available in online portals (22, 30, 35). Unsurprisingly, other electronic sources such as mass media, smartphones, audio-visual materials and DVDs ranked equally as high as the Internet, as a preferred source of information (26, 28, 33, 35). The electronic sources requested were not dissimilar to the current electronic sources already utilised by patients and their informal caregivers. Patients and caregivers showed equal preference for written information sources and both online and face-to-face support groups (50%), despite those sources not being one of the top three current information sources (26, 27, 34, 35). Electronic medical records, educational conferences, government services and healthcare professionals were also reported as desired information sources, in one study each (Table 4, Figure 2).

In addition to the abovementioned sources, one study also stated additional preferences on how information should be presented (35). Having information in multiple sources and languages was preferred, in order to increase its accessibility to linguistically diverse communities. Information presented through these sources should also be individualised to the different dementia syndromes and stages of the disease, as the concerns of these patients and caregivers could vary widely.

**Discussion**

We identified 20 studies (4,140 participants) reporting the information needs and information seeking behaviour of dementia patients and their caregivers. Studies mostly focused on the information needs and information seeking behaviour of dementia caregivers, were conducted in high income countries and involved predominantly female caregivers. Dementia health services related information was the most commonly reported information need in the included studies. The most diverse information needs related to patient care. Severity of dementia and patient/caregiver status were the only variables observed to affect information needs of dementia caregivers and patients. Information seeking behaviour was reported in 14 studies, and active searching behaviour was the most commonly reported type of information behaviour. Currently, there is a lack of evidence focused on the information needs and information seeking of dementia patients, and patients with different types of dementia. More research is also required for populations in low- and middle-income countries, and for comparison of the impact of different variables on information needs and information seeking behaviour.

The results of this current review suggest that the type of information most often requested by dementia patients and their caregivers was where to find and use available dementia-focused healthcare services (14 out of 20 studies; Table 2). Surprisingly, this contradicted most of the available literature that we have seen. Systematic reviews exploring the needs of informal dementia care providers indicated that the most frequently reported information need was information on the disease, followed by patient care information (11, 40). There could be several reasons for this inconsistency. We included several studies that were published after the dates of these reviews. As such, studies that were more recently published could have implied there was a shift in the focus of information needs away from the disease and towards available help and services. At the point of diagnosis, the patients and their caregivers could have been counselled on the condition to help them understand and accept the condition. However, information about formal care services may not always be adequately provided at the point of diagnosis, and this information becomes more pertinent as the patient’s condition declines (41). As seen in our results, the severity of the patient’s dementia condition also affects the type of information required by their caregivers and the patients themselves. While we are unable to establish if this was a definite contributor to the difference in information needs as both reviews did not provide the stages of dementia for their included studies, this could have also affected the information needs reported as caregivers usually need more help in the later stages of dementia, following the worsening of behavioural and psychological symptoms of dementia. Another possible reason would be that the focus of these systematic reviews was not on information needs, but rather on general needs, and thus did not include some of the studies and information needs that were mentioned in the current review.

In order to better understand the information preferences of dementia patients and their informal caregivers, we also evaluated their information seeking behaviour and information sources utilised. It was reported that the most desired source of information was the one that patients and caregivers most frequently utilised (i.e. the Internet). This suggests that their information needs were unmet while using the Internet, as a result of the inability of these groups to find the information they need or the inadequacy of information available on specific websites or portals that were accessed (42, 43). Our results seem to suggest that the latter was a more likely reason, as participants indicated specific resources they wished to find on the Internet, such as videos and frequently asked questions (FAQs) websites (see Table 4). The sentiment on being unable to find the specific types of information they were looking for across various information sources has also been echoed in existing literature (11). The inability to find specific information may not be due to a lack of information, but in certain cases it could also be presented in a form that was difficult to understand by patients and their caregivers. Information on the disease could have been
presented using medical terms that people were not familiar with. Often, the amount of information available could be overwhelming for patients and their care providers to sort through, leading them to miss what they were looking for even if it was readily available. Despite only one study in our review emphasising the need for targeted and timely information to dementia patients and their caregivers, this need is not unique based on types and severity of dementia. This was also previously iterated in two reviews (11, 44). Future interventions focusing on information provision should take these into account when developing information resources.

An interesting finding from our review was that the top sources of information that dementia patients and caregivers preferred were electronic sources such as the Internet, mass media and smartphones. This was unexpected given that the mean ages of caregivers were between 55 to 70 years, and between 70 to 90 years for the patients. Existing literature to date suggests that electronic sources were not preferred as health information sources due to a lack of awareness about what these sources could offer, rather than cost or access-related reasons (45). As internet adoption among older adults have steadily increased over the years, the purposes for which they used the Internet for could also have changed. In 2003, the use of the Internet in older adults were mainly confined to email and general information seeking but more recent analyses in 2009 show that in addition to those purposes, health information seeking was placed as one of the more common online activities (46). Electronic sources are able to offer a variety of information independent of time and location, which could be the reason for their growing popularity as a health information source. This growing trend of information retrieval from electronic sources is not limited to the Internet but could also encompass apps for dementia care on smartphones and programmes on mass media sources (47, 48). Our results also identified active searching behaviour as the most common information searching behaviour amongst all included studies, highlighting the growing acceptance of new information sources (such as smartphones and the Internet) that were previously not used by dementia patients and caregivers.

Patients and caregivers also showed a preference for written information and support groups as information sources over healthcare professionals. Healthcare professionals were usually the first information source that patients and caregivers would encounter, with information about the condition being provided at point of diagnosis. However, several studies within our review expressed that the information provided was insufficient and that further information was also not provided at subsequent follow up appointments (22, 28, 31, 34). The information provided by healthcare professionals could be of a medical nature (such as medications to manage the condition), while patients and caregivers may desire information regarding the prognosis of the condition or available community care resources and entitlements. This finding again highlights the mismatch between information needs and information sources, where healthcare professionals may not necessarily be unable to provide the information required but could be unaware of these other information needs of the patients and caregivers. Support groups and written information sources could also be more highly preferred due to their ability to provide an array of information beyond medical information.

Limitations and future research directions

Our review identified several limitations. We were unable to ascertain the severity of dementia for the patients, and if the participants included in some studies were truly the primary caregivers for dementia patients, as some surveys were returned through the post or online. While we did not set restrictions on the geographical regions of where studies were conducted, all studies were conducted in high income countries such as the USA and UK, therefore the findings may not be applicable to other geographical regions or even rural areas within these countries. Furthermore, the search strategy was limited to studies published in English and we may have missed relevant articles that were published in other languages. Most of the studies included addressed mainly the information needs and information seeking behaviour of the caregivers, and only four studies addressed the needs of both patients and caregivers. Some studies recruited participants through self-selection, therefore they may already be more highly educated, have higher income levels and increased informational needs and already be more active in searching for information.

Our scoping review highlights that the mismatch between information needs and information sources is not due to access, but rather the inability to find specific information across various sources. Rather than finding new ways and platforms to deliver information to patients and their caregivers, which would result in further fragmentation of available information, effort should be made to consolidate information on
specific sites or platforms that are already in use (e.g. Alzheimer’s Association website). Future interventions targeted at information provision should focus on utilising familiar platforms to deliver information pertaining to healthcare services while ensuring that the information is available in different languages.

Most of the studies included in the review used mainly cross-sectional (21, 23-27, 29, 32, 36, 38, 49) or qualitative study designs (20, 22, 28, 30, 33-35, 37). Future research should consider the use of longitudinal study designs, in order to further identify information needs of patients and caregivers at various stages of their disease – from diagnosis where disease related information may be more desired, to the more advanced stages where help may be sought on providing adequate care to the patient. With the advances in technologies, future research should explore how information can be delivered in a targeted manner based on different types of digital technologies, such as through smartphones. The use of mobile phone technologies for health professions education has seen great effectiveness and is also a cost-effective and accessible alternative to printed information sources (50). Since there is already an indicated preference for electronic sources, this approach could similarly be adapted to deliver information to dementia patients and caregivers.

Conclusions

This scoping review provides an overview of the literature on the information needs and information seeking behaviour of dementia patients and caregivers. Information needs of patients and caregivers can be categorised into four themes – disease related information, healthcare services-related information, patient care provision and caregiver self-care. Information on healthcare services need to be emphasised by healthcare professionals at consultations and through preferred electronic and written sources. Caregiver self-care was also another information need that was frequently overlooked, and future research should focus on evaluation of this information need. The only variable found to significantly influence information needs was the severity of dementia. Information needs between caregivers and patients were found to be largely consistent, however, more research is required on this area as this was only highlighted by one study. Patients and caregivers actively sought for information and preferred using the Internet to look for desired information. Future interventions on information delivery to dementia patients and caregivers should focus on having required information on central platforms such as the Alzheimer’s Association website and emphasise the use of preferred electronic sources. Future research should aim to evaluate the information needs of patients and caregivers at specific stages, across various dementia syndromes and focus on variables that affect these information needs.

Declarations

List of abbreviations

Alzheimer’s disease = AD, frontotemporal dementia = FTD, Lewy Body dementia = LBD, Electronic medical records = EMR, digital versatile disc = DVD, frequently asked questions = FAQs, General practitioner = GP, European Union = EU

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Availability of data and material

This scoping review included the data extracted from the primary studies. The whole set of data extraction sheet is available upon request.

Competing interests

The authors declare that they have no competing interests.

Funding
Authors' contributions

LTC conceived the idea for the project. AS and AST wrote the paper. LTC provided the methodological guidance and critical inputs for the review. LTC, AST, BMK and TYL reviewed the article and provided the comments.

Acknowledgements

We gratefully acknowledge funding from the Lee Kong Chian School of Medicine, Nanyang Technological University Singapore, Singapore.

References

1. Prince M, Anders W, Guerchet M, Ali G, Wu Y, Prina M. The Global Impact of Dementia: An analysis of prevalence, incidence, cost and trends. World Alzheimer’s Report 2015 [Internet]. 2015.
2. United Nations. World Population Prospects: The 2017 Revision, Key Findings and Advance Tables. 2017.
3. World Health Organization. Dementia2018. Available from: https://www.who.int/news-room/facts-in-pictures/detail/dementia.
4. Brodaty H, Donkin M. Family caregivers of people with dementia. Dialogues in Clinical Neuroscience. 2009;11(2):217-28.
5. Wimo A, Guerchet M, Ali G-C, Wu Y-T, Prina AM, Winblad B, et al. The worldwide costs of dementia 2015 and comparisons with 2010. Alzheimer’s & Dementia. 2017;13(1):1-7.
6. Greenfield S, Kaplan S, Ware JE, Jr. Expanding patient involvement in care. Effects on patient outcomes. Annals of internal medicine. 1985;102(4):520-8.
7. Mazzuca SA. Does patient education in chronic disease have therapeutic value? Journal of chronic diseases. 1982;35(7):521-9.
8. Dutta-Bergman M. Trusted Online Sources of Health Information: Differences in Demographics, Health Beliefs, and Health-Information Orientation. Journal of Medical Internet Research. 2003;5(3):e21.
9. Hesse BW, Nelson DE, Kreps GL, et al. Trust and sources of health information: The impact of the internet and its implications for health care providers: findings from the first health information national trends survey. Archives of Internal Medicine. 2005;165(22):2618-24.
10. Thompson CA, Spilsbury K, Hall J, Birks Y, Barnes C, Adamson J. Systematic review of information and support interventions for caregivers of people with dementia. BMC Geriatrics. 2007;7(1):18.
11. McCabe M, You E, Tatangelo G. Hearing Their Voice: A Systematic Review of Dementia Family Caregivers’ Needs. The Gerontologist. 2016;56(5):e70-e88.
12. Waligora KJ, Bahouth MN, Han H-R. The Self-Care Needs and Behaviors of Dementia Informal Caregivers: A Systematic Review. 2018.
13. Levac D, Colquhoun H, O’Brien KK. Scoping studies: advancing the methodology. Implementation Science. 2010;5(1):69.
14. Tricco AC, Lillie E, Zarin W, O’Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and ExplanationThe PRISMA-ScR Statement. Annals of internal medicine. 2018;169(7):467-73.
15. Weijts W, Widdershoven G, Kok G, Tomlow P. Patients’ Information-Seeking Actions and Physicians’ Responses in Gynecological Consultations1993. 398-429 p.
16. Arksey H, O’Malley L. Scoping studies: towards a methodological framework. International Journal of Social Research Methodology. 2005;8(1):19-32.
17. Wilson TD. Human Information Behavior. Informing Science. 2000;3(2).
18. Kuske S, Schiereck T, Grobosch S, Paduch A, Droste S, Halbach S, et al. Diabetes-related information-seeking behaviour: a systematic review. Systematic Reviews. 2017;6(1):212.
19. Ducharme F, Kergoat M-J, Coulombe R, Lévesque L, Antoine P, Pasquier F. Unmet support needs of early-onset dementia family caregivers: a mixed-design study. BMC Nursing. 2014;13(1):1-20.
20. Forbes DA, Finkelstein S, Blake CM, Gibson M, Morgan DG, Markle-Reid M, et al. Knowledge exchange throughout the dementia care journey by Canadian rural community-based health care practitioners, persons with dementia, and their care partners: an interpretive descriptive study. Rural Remote Health. 2012;12(4):2201.
21. Hirakawa Y, Kuzuya M, Enoki H, Uemura K. Information needs and sources of family caregivers of home elderly patients. Arch Gerontol Geriatr. 2011;52(2):202-5.
22. Huis JG, Verkaik R, van Meijel B, Verkade PJ, Werkman W, Hertogh CMPM, et al. Self-Management Support and eHealth When Managing Changes in Behavior and Mood of a Relative With Dementia: An Asynchronous Online Focus Group Study of Family
23. Koenig KN, Steiner V, Pierce LL. Information needs of family caregivers of persons with cognitive versus physical deficits. Gerontol Geriatr Educ. 2011;32(4):396-413.

24. Rosa E, Lussignoni G, Sabbatini F, Chiappa A, Di Cesare S, Lamanna L, et al. Needs of caregivers of the patients with dementia. Archives of Gerontology and Geriatrics. 2010;51(1):54-8.

25. Thomas P, Chantoin-Merlet S, Hazif-Thomas C, Belmin J, Montagne B, Clément J-P, et al. Complaints of informal caregivers providing home care for dementia patients: the Pixel study. International Journal of Geriatric Psychiatry. 2002;17(11):1034-47.

26. Galvin JE, Duda JE, Kaufer DI, Lippa CF, Taylor A, Zarit SH, et al. Lewy body dementia: caregiver burden and unmet needs. Alzheimer Disease & Associated Disorders. 2010;24(2):177-81.

27. Killen A, Flynn D, De Brún A, O’Brien N, O’Brien J, Thomas AJ, et al. Support and information needs following a diagnosis of dementia with lewy bodies. International Psychogeriatrics. 2016;28(3):495-501.

28. Boughtwood D, Shanley C, Adams J, Santalucia Y, Kyriazopoulos H, Pond D, et al. Dementia information for culturally and linguistically diverse communities: sources, access and considerations for effective practice. Aust J Prim Health. 2012;18(3):190-6.

29. Georges J, Jansen S, Jackson J, Meyrieux A, Sadowska A, Selmes M. Alzheimer’s disease in real life - the dementia carer’s survey. International Journal of Geriatric Psychiatry. 2008;23(5):546-51.

30. Iribarren S, Stonbraker S, Suero-Tejeda N, Granja M, Luchsinger JA, Mittelman M, et al. Information, communication, and online tool needs of Hispanic family caregivers of individuals with Alzheimer’s disease and related dementias. Inform Health Soc Care. 2018:1-20.

31. Jensen CJ, Inker J. Strengthening the dementia care triad: Identifying knowledge gaps and linking to resources. American Journal of Alzheimer's Disease and Other Dementias. 2015;30(3):268-75.

32. Scharett E, Madathil KC, Lopes S, Rogers H, Agnisarman S, Narasimha S, et al. An Investigation of the Information Sought by Caregivers of Alzheimer’s Patients on Online Peer Support Groups. Cyberpsychol Behav Soc Netw. 2017;20(10):640-57.

33. Shreve J, Baier RR, Epstein-Lubow G, Gardner RL. Dementia caregivers’ technology preferences: Design insights from qualitative interviews. Gerontechnology. 2016;14(2):89-96.

34. Turner A, Street HP. Assessing carers’ training needs: a pilot inquiry. Aging & Mental Health. 1999;3(2):173-8.

35. Vaingankar JA, Subramaniam M, Picco L, Eng GK, Shafie S, Sambasivram R, et al. Perceived unmet needs of informal caregivers of people with dementia in Singapore. International Psychogeriatrics. 2013;25(10):1605-19.

36. Wackerbarth SB, Johnson MM. Essential information and support needs of family caregivers. Patient Educ Couns. 2002;47(2):95-100.

37. de Jong JD, Boersma F. Dutch psychogeriatric day-care centers: A qualitative study of the needs and wishes of carers. International Psychogeriatrics. 2009;21(2):268-77.

38. Edelman P, Kuhn D, Fulton BR, Kyrouac GA. Information and service needs of persons with Alzheimer’s disease and their family caregivers living in rural communities. American Journal of Alzheimer’s Disease & Other Dementias. 2006;21(4):226-33.

39. Hirakawa Y, Kuzuya M, Enoki H, Uemura K. Information needs and sources of family caregivers of home elderly patients. Archives of gerontology and geriatrics. 2011;52(2):202-5.

40. Novais T, Dauphinot V, Krolak-Salmon P, Mouchoux C. How to explore the needs of informal caregivers of individuals with cognitive impairment in Alzheimer’s disease or related diseases? A systematic review of quantitative and qualitative studies. BMC Geriatr. 2017;17(1):86.

41. Stephan A, Bieber A, Hopper L, Joyce R, Irving K, Zanetti O, et al. Barriers and facilitators to the access to and use of formal dementia care: findings of a focus group study with people with dementia, informal carers and health and social care professionals in eight European countries. BMC geriatrics. 2018;18(1):131.

42. Robinson A, Elder J, Emden C, Lea E, Turner P, Vickers J. Information pathways into dementia care services: Family carers have their say. Dementia. 2009;8(1):17-37.

43. Weih M, Reinhold A, Richter-Schmidinger T, Sulimma AK, Klein H, Kornhuber J. Unsuitable readability levels of patient information pertaining to dementia and related diseases: a comparative analysis. Int Psychogeriatr. 2008;20(6):1116-23.

44. Etters L, Goodall D, Harrison BE. Caregiver burden among dementia patient caregivers: a review of the literature. Journal of the American Academy of Nurse Practitioners. 2008;20(8):423-8.

45. Helser PJ, Reisdorf BC. A quantitative examination of explanations for reasons for Internet nonuse. Cyberpsychology, Behavior, and Social Networking. 2013;16(2):94-9.

46. Jones S, Fox S. Generations Online in 20092009. Available from: http://www.pewinternet.org/2009/01/28/generations-online-in-2009/.

47. Grossman MR, Zak DK, Zelinski EM. Mobile Apps for Caregivers of Older Adults: Quantitative Content Analysis. JMIR mHealth and uHealth. 2018;6(7):e162-e.

48. Lai L. New mobile app launched to help caregivers of people with dementia. The Straits Times. 2018.

49. Steiner V, Pierce LL, Salvador D. Information Needs of Family Caregivers of People With Dementia. Rehabilitation Nursing. 2016;41(3):162-9.
50. Dunleavy G, Nikolaou CK, Nifakos S, Atun R, Law GCY, Tudor Car L. Mobile Digital Education for Health Professions: Systematic Review and Meta-Analysis by the Digital Health Education Collaboration. J Med Internet Res. 2019;21(2):e12937.
| Study, Year, Country | Characteristics | Study Design and Data Collection Methods | Participants | Gender | Age | Caregiver’s Relationship with Patient | Duration of Caregiving | Education Level of Caregiver | Study Objective |
|----------------------|-----------------|----------------------------------------|---------------|--------|-----|-------------------------------------|------------------------|-----------------------------|------------------|
| Boughtwood 2012, Australia | Qualitative | (Focus groups, Interviews) | 121 family carers, 16 GPs, 20 geriatricians, 24 bilingual and bicultural workers | 88 female, 33 male family carers | 17-90 | Not mentioned | Not mentioned | Not mentioned | To examine dementia-related information needs, access and delivery issues in Arabic, Chinese, Italian and Spanish-speaking communities south-west Sydney, Australia |
| de Jong 2009, Netherlands | Qualitative | (Semi-structured interviews) | 9 family caregivers | 5 females, 4 males family caregivers | Patients age range: 67 - 88 | 2 husbands, 2 wives, 2 sons, 2 daughters, 1 daughter-in-law | Not mentioned | Not mentioned | To explore needs and wishes of informal caregivers of people with dementia attending or formerly attending skilled psychogeria day-care in Netherlands |
| Durcharne 2014, Canada | Mixed methods | (Interviews, Questionnaire) | 32 family caregivers | 24 female, 8 male | Mean: 54.28, SD: 10.5 | 25 spouse, 5 offspring, 2 other | Mean: 83.7 hours per week, SD: 61.4 hours | Mean: 14.34 years, SD: 3.2 years | To document the unmet support needs of early-onset dementia family caregivers |
| Edelman 2006, USA | Cross sectional | (22 item Checklist Survey) | 100 family caregivers, 100 dementia patients (caregivers paired with patients) | 61 female, 39 male caregivers, 70 female and 30 male patients. | Mean: 61, SD: 13 for caregivers, Mean: 80, SD: 6 for patients | 44 spouse, 36 mother/mother-in-law, 10 father/father-in-law, 10 other relationship | Not mentioned | 64 with high school education or less, 24 had some college education, 8 were college graduates and 4 attended graduate school. | To identify information and service needs of persons with Alzheimer’s disease and their family caregivers living in rural communities and to assess differences and similarities in each partner’s perspective |
| Hirakawa 2009, Japan | Cross sectional | (Self-reported Structured Questionnaire) | 475 family caregivers | 366 female, 109 male | Mean: 64.9, SD: 12.2 | 205 spouse, 235 child (including daughter/son-in-law), 29 others | Not mentioned | Junior high: 39, High School - 200, University - 97 | To explore the following two areas: (a) the priority information needs and sources of family caregivers of home elderl patients and (b) the differences in information needs according to the severity of dementia |
| Forbes 2012, Canada | Qualitative | (Interviews) | 14 care providers, 5 patients with dementia, 14 healthcare practitioners | 11 female, 3 male care providers, 2 female, 3 male patients. | Mean: 60.31, SD: 15.74 for care providers, Mean: 77.40, SD: 6 | 6 spouse, 5 children, 2 grandchildren, 1 nephew | Not mentioned | 1 Caregiver had primary or less, 6 had secondary education and 6 finished post-secondary education and 6 finished post-secondary education | To enable healthcare practitioners to care for patients with dementia and to enable dementia caregivers to have access to resources and support networks |

Table 1. Characteristics of the included studies
| Study | Design | Sample Size | Gender Distribution | Mean Age | SD | Caregiver Education | Patient Education | Primary Caregiver | Additional Details |
|-------|--------|-------------|---------------------|----------|----|---------------------|------------------|------------------|-------------------|
| Galvin 2010, USA | Cross sectional (Internet based survey) | 971 caregivers | 87.9% female, 12.1% male caregivers | Mean: 55.9, SD: 12 for caregiver | Mean: 75.4, SD: 8.4 for patients | 40.6% spouse, 51.7% child, 3.8% other relative, 3.8% friend | Not mentioned | 0.6% had less than high school education, 25.5% had high school education, 73.8% had college education or higher. | To ascertain the unmet needs of Lewy body dementia caregivers and collect data informing educational programming and enhance caregiver support. |
| Georges 2008, Europe and UK | Cross sectional (Self-completed Questionnaire) | 1181 carers | 67% female, 33% male | 65% ≥ 55 years of age, 33% < 55 years of age | 47% spouse, 37% parent. | Not mentioned | Not mentioned | To identify caregivers’ needs and differences between countries with regard to dementia care and the level of satisfaction carers utilize services. |
| Huis 2018, Netherlands | Qualitative (Online focus groups) | 36 family caregivers | 32 female, 4 male | Mean: 61, SD: 42-61 | 19 child or child-in-law, 17 partner | Not mentioned | Not mentioned | To discuss how and by whom family caregivers want to be supported in self-management when managing changes in behaviour and mood of relatives with dementia, and whether family caregivers consider eHealth a useful tool for self-management support. |
| Iribarren 2018, USA | Qualitative (Participatory design session consisting of open dialogue, interactive feedback and browsing the internet, and a questionnaire) | 24 caregivers | 19 female, 5 male | Mean: 59.7, SD: 7.67 | 16 child, 6 spouse, 2 other relative | Mean: 6.5 years, SD: 4.7 years | 1 completed eight grade or less, 12 completed all or some of high school, 10 had a degree beyond high school. | To identify caregiver attributes that may influence the use of Family Health Information Management System, caregiver information and communicative needs and tasks, and caregiver perceptions online tools meet these needs. |
| Jensen 2015, USA | Mixed methods (Telephone survey, Online survey) | 128 caregivers, 27 health care providers | 76% female, 24% male | Mean: 62.5, SD: 12.5 | 47.6% child or child-in-law, 36.5% spouses. | 3 years or more: 68.3%, Between 3-5 years: 38.9%, 8 or more years: nearly | 17 completed some high school or had a high school degree, 34 completed some college. | To identify the needs of family caregivers and healthcare providers caring for persons with dementia, and characterize how they access, assess and apply this knowledge more effectively. |
| Study                  | Design          | Sample Size | Demographics                  | Findings                                                                                           |
|------------------------|-----------------|-------------|-------------------------------|---------------------------------------------------------------------------------------------------|
| Killen 2016, UK        | Cross sectional | 122 caregivers, 3 patients | 89% female, 11% male | 33 had a college degree, 33 completed some graduate school/had a graduate degree, 11 did not report education level. They interact with the care recipient’s health care provider. |
| Killen 2016, UK        | Cross sectional | (Internet survey) | Not mentioned                     | Not mentioned. To explore the information and support needs of people with Lewy bodies and their caregivers around the point of diagnosis, in order to inform the development of a theory-based intervention to improve coping with stress and increase quality of life. |
| Koenig 2011, USA       | Cross sectional | 33 dementia caregivers, 40 rehabilitation caregivers | Mean: 62.2, 14 mother, 11 spouse, 4 father, 3 other, 1 friend | Mean: 30.6 months of schooling. To compare information needs of caregivers to persons with dementia with caregivers to those who received rehabilitative treatment. |
| Koenig 2011, USA       | Cross sectional | (48-item Survey)       | Mean: 80, SD: 8 for patients | Not mentioned. To isolate the needs caregivers express with the following critical areas: medical, social, psychological, and educational, the effect of providing to ones with support services capable of decreasing caregiving-related workloads. |
| Rosa 2010, Italy       | Cross sectional | 112 primary caregivers | 77 female, 35 male | Not mentioned. To understand the characteristic of information design and functionality family caregivers. |
| Rosa 2010, Italy       | Cross sectional | (Questionnaire) | Mean: 55, SD: 10 for caregivers. | Not mentioned. To understand the information technology design characteristic and functionality family caregivers. |
| Scharett 2017, USA     | Cross sectional | Alzheimer’s caregivers³ | Not mentioned                     | Not mentioned. To understand the characteristic of information design and functionality family caregivers. |
| Scharett 2017, USA     | Cross sectional | (Analysis of forum posts) | Not mentioned                     | Not mentioned. To understand the characteristic of information design and functionality family caregivers. |
| Shreve 2016, USA       | Qualitative     | 12 family caregivers | 11 female, 1 male | Not mentioned. To determine which information technology design characteristic and functionality family caregivers... |
| Study | Design Type | Sample Size | Participants | Study Aim |
|-------|-------------|-------------|--------------|-----------|
| Thomas 2002, France | Cross sectional | 408 caregiver/patient pairs | 236 female, 172 male patients. 276 female, 126 male caregivers. Female caregivers: 60.66 ± 0.79, Male caregivers: 68.7 ± 1.13. Female patients: 77.1 ± 0.47, male patients: 75.7 ± 0.57 | Not mentioned | Not mentioned | To determine the complain of home caregivers, how they are interrelated and what causes them |
| Turner 2010, UK | Qualitative | 30 carers | 18 female, 12 male | 2/3 of carers were under 65 years of age | 70% of carers had been carers for 2 years or more. | Not mentioned | To assess the needs for training of family carer of people with dementia, a part of an E project to develop a training package for carers |
| Vaingankar 2013, Singapore | Qualitative | 63 informal caregivers | 38 female, 25 male | Patients age range: 54 to 93 | Not mentioned | 5 none/some primary education, 10 secondary/Junior college education, 23 vocational education, 24 university education | To elucidate the perceived unmet needs of informal caregivers of people with dementia in Singapore |
| Wackerbarth 2002, USA | Cross sectional | 128 caregivers | 93 female, 35 male | Mean: 58.7, Range: 34-85 for caregivers. Mean: 78.5, Range: 53-96 for patients. | Children of patient (64.5%), spouse of patient (34.7%) | Mean: 4.7 years, Range 6 months to 8 years. | Mean of 14.6 years of education, range 8-22 years. 1.6% had primary education only, 32% completed high school, 62.8% had some college education. | To identify the essential information and support needs of family caregivers of individuals with Alzheimer’s disease or a related dementia, to examine the relationship between caregiver characteristics and needs |

Table 2: Information needs themes of caregivers and dementia patients (n = 20 articles)
| Theme                                | Information need                                                                 | Number and percentage of studies<sup>1</sup> | References for information need |
|-------------------------------------|----------------------------------------------------------------------------------|-----------------------------------------------|---------------------------------|
| Disease-specific information        | General information on dementia                                                   | 10 (62.5%)                                    | (24, 27, 30-32, 34, 36, 37)     |
|                                     | Dementia Treatment                                                                | 7 (43.7%)                                     | (19-21, 26, 35, 36, 38)         |
|                                     | Identifying and understanding dementia  
  eg. typical symptoms of dementia/ behaviour                                  | 6 (37.5%)                                     | (21, 27, 32, 34, 35, 38)        |
|                                     | Dementia prognosis                                                                 | 6 (37.5%)                                     | (20, 21, 25, 29, 31, 33)        |
|                                     | Current dementia medication                                                        | 5 (31.2%)                                     | (24, 27, 30, 32, 38)           |
|                                     | Experimental drugs/Clinical trials                                                | 4 (25%)                                       | (20, 26, 36, 38)                |
|                                     | Current research on dementia                                                      | 3 (18.7%)                                     | (26, 27, 36)                    |
|                                     | Genetic aspects of the disease                                                    | 2 (12.5%)                                     | (27, 38)                       |
|                                     | Negative impact of dementia on family and community                               | 1 (0.06%)                                     | (21)                           |
|                                     | Information specific to different stages of dementia                             | 1 (0.06%)                                     | (35)                           |
|                                     | Chance of recovery                                                                | 1 (0.06%)                                     | (21)                           |
|                                     | Memory Skills                                                                     | 1 (0.06%)                                     | (27)                           |
| Patient Care Provision information  | How to care for the patient                                                       | 7 (53.8%)                                     | (22-24, 27, 28, 37, 38)        |
|                                     | eg. general care, patient hygiene, food and nutritional information, best attitudes to adopt in caring |                                           |                                 |
|                                     | How to deal with patient’s behaviour                                              | 6 (46.1%)                                     | (22-24, 27, 28, 37)           |
|                                     | Safety issues                                                                    | 5 (38.4%)                                     | (19, 20, 27, 32, 37)           |
|                                     | eg. how to improve safety of environment, how to keep patient safe, how to recognise fall risks and poor mobility |                                           |                                 |
|                                     | Coping with hallucinations                                                        | 2 (15.3%)                                     | (23, 27)                       |
|                                     | Communication difficulties and how to manage them                                  | 2 (15.3%)                                     | (27, 38)                       |
|                                     | Patient activities                                                               | 2 (15.3%)                                     | (30, 38)                       |
|                                     | First aid and medical information                                                | 2 (15.3%)                                     | (21, 37)                       |
|                                     | Emergency situations                                                             | 2 (15.3%)                                     | (19, 35)                       |
|                                     | Conflict resolution                                                              | 1 (0.07%)                                     | (32)                           |
|                                     | Patient Ethics                                                                  | 1 (0.07%)                                     | (32)                           |
| Information Need                                                                 | Count (%)                | References |
|--------------------------------------------------------------------------------|--------------------------|------------|
| Helpful experiences of other caregivers                                       | 1 (0.07%)                | (27)       |
| How to deal with family and friends                                            | 1 (0.07%)                | (38)       |
| How to advocate for patient                                                    | 1 (0.07%)                | (20)       |
| When to transfer patient to hospital                                           | 1 (0.07%)                | (21)       |
| **Healthcare Service-related**                                                 |                          |            |
| Where and how to use services/help available                                   | 14 (93.3%)               | (19-21, 24, 26-29, 31, 32, 34-36, 38) |
| e.g. geriatric hospitals, nursing homes, support groups, physicians skilled in diagnosis and treatment |                          |            |
| Financial help and services                                                    | 5 (33.3%)                | (19, 31, 32, 34, 36) |
| Legal issues                                                                   | 4 (26.6%)                | (20, 21, 32, 36) |
| How to apply for care programs                                                 | 2 (13.3%)                | (20, 24)   |
| e.g. day care, long term care                                                  |                          |            |
| Insurance                                                                      | 2 (13.3%)                | (30, 36)   |
| Home Help                                                                      | 1 (0.07%)                | (25)       |
| Transportation options                                                         | 1 (0.07%)                | (20)       |
| **Caregiver self-care**                                                        |                          |            |
| Stress Management                                                              | 2 (50%)                  | (21, 23)   |
| Carer's entitlements (pension)                                                 | 1 (25%)                  | (28)       |
| Managing emotions                                                              | 1 (25%)                  | (23)       |
| General caregiver self-care                                                    | 1 (25%)                  | (30)       |
| e.g. exercise, diet, own medications                                          |                          |            |

1Percentage of studies refer to the percentage of studies in each reported information need contributing towards the main theme.

Table 3: Information needs classified according to severity of dementia
| Author (reference), year | Severity of dementia | Information needs |
|-------------------------|----------------------|------------------|
| Edelman (38), 2006      | Mostly mild          | 1. Identifying and understanding dementia  
                        2. Experimental drugs  
                        3. Current dementia medication  
                        4. Genetic aspects of the disease  
                        5. Current research on dementia  
                        6. Where and how to use services/help available |
| Hirakawa (39), 2011     | Mostly mild          | 1. General information on dementia  
                        2. First aid and medical information  
                        3. How to care for the patient  
                        4. When to transfer patient to hospital  
                        5. How to apply for care programs |
| de Jong (37), 2009      | Mostly moderate - severe | 1. General information on dementia  
                        2. Identifying and understanding dementia  
                        3. Dementia prognosis  
                        4. How to deal with patient’s behaviour  
                        5. Safety issues  
                        6. Medical information  
                        7. Where and how to use services/help available |
| Rosa (24), 2010         | Mostly moderate - severe | 1. General information on dementia  
                        2. Identifying and understanding dementia  
                        3. Current dementia medication  
                        4. How to deal with patient’s behaviour  
                        5. How to apply for care programs  
                        6. Where and how to use services/help available  
                        7. Financial help and services |

*Table 4: Current and preferred information sources on dementia in the included studies*
| Information Sources                          | Number and percentage of studies | References for each source |
|---------------------------------------------|----------------------------------|----------------------------|
| Current sources                             |                                  |                            |
| Internet - Websites and forums              | 10 (71.4%)                      | (19-22, 28, 30-33, 38)     |
| Healthcare professionals                    | 7 (50%)                          | (20-22, 27, 31, 35, 36)    |
| Family/friends                              | 6 (42.8%)                        | (20-22, 27, 28, 36)        |
| Alzheimer's Association website             | 5 (35.7%)                        | (20, 22, 28, 31, 36)       |
| Electronic sources – email, smartphone apps (eg. Alzheimer's Assistant), videos, TV | 5 (35.7%)                        | (22, 25, 30, 32, 35)       |
| Written information - books, leaflets, newsletters, newspapers, magazines | 4 (28.5%)                        | (21, 25, 31, 32)           |
| Support groups                              | 4 (28.5%)                        | (20, 30, 31, 36)           |
| Care centres                                | 2 (14.2%)                        | (20, 36)                   |
| Social worker                               | 2 (14.2%)                        | (27, 36)                   |
| Other family caregivers                      | 2 (14.2%)                        | (22, 35)                   |
| Volunteer groups/ organizations             | 2 (14.2%)                        | (21, 27)                   |
| Clergy                                      | 1 (0.07%)                        | (36)                       |
| Bank employees                              | 1 (0.07%)                        | (20)                       |
| Preferred sources                           |                                  |                            |
| Internet - Website page with FAQs, how-to videos, online portals | 4 (66.6%)                        | (22, 30, 33, 35)           |
| Electronic sources – mass media, audio-visual materials, DVDs, smartphones | 4 (66.6%)                        | (26, 28, 33, 35)           |
| Support groups                              | 3 (50%)                          | (26, 27, 34)               |
| Written information                         | 3 (50%)                          | (26, 34, 35)               |
| Electronic medical records (EMR)            | 1 (16.6%)                        | (30)                       |
| Educational conferences                     | 1 (16.6%)                        | (26)                       |
| Government services                         | 1 (16.6%)                        | (28)                       |
| Healthcare professionals                    | 1 (16.6%)                        | (28)                       |

**Figures**
Figure 1

Study flow diagram

Figure 2

Percentage of Studies indicating Current and Preferred Information Sources

Supplementary Files
This is a list of supplementary files associated with this preprint. Click to download.

- PRISMAcRFFillableChecklistdementiascopingv2.docx