HEALTH LITERACY AND KNOWLEDGE OF DEMENTIA: A SCOPING REVIEW OF CAREGIVERS AND COMMUNITY PERSPECTIVES

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ABSTRACT

***Background**: Dementia has become increasingly as a consequence of global aging. However, low levels of health literacy and limited knowledge about dementia often hinder effective caregiving. Stigma surrounding dementia in society also poses a significant barrier to proper care. **Purpose**: This scoping review aimed to identify the characteristics of studies examining dementia-related literacy and knowledge among caregivers and communities. **Method:** This scoping review search was conducted through Scopus, PubMed, and ProQuest databases using the PRISMA-ScR guideline. **Results**: Six of the studies used a cross-sectional design, while one employed a qualitative approach. The main findings showed low health literacy on dementia, varied levels of dementia knowledge, sociodemographic influences, stigma and societal perceptions, and caregiving challenges. **Conclusion**: Literacy and knowledge levels regarding dementia remain low, influenced by factors such as age, gender, education, income, residence location, and prior caregiving experience. Stigma was found to increase the caregiving burden and reduce the quality of care.*

***Keyword**: Caregiver, Dementia, Health Literacy, Older Adults*

Latar Belakang: Demensia semakin banyak seiring bertambahnya usia populasi dunia. Rendahnya literasi kesehatan dan pengetahuan tentang demensia serta stigma sosial menjadi hambatan dalam pemberian perawatan yang efektif. **Tujuan**: Meninjau karakteristik studi terkait literasi dan pengetahuan demensia pada caregiver dan masyarakat. **Metode***:* *Scoping review* dilakukan melalui database Scopus, PubMed, dan ProQuest menggunakan pedoman PRISMA-ScR. **Hasil**: enam artikel bersifat potong lintang dan satu kualitatif. Temuan mencakup rendahnya literasi dan pengetahuan tentang demensia, pengaruh faktor sosiodemografis, stigma, dan tantangan dalam perawatan. **Kesimpulan**: Tingkat literasi dan pengetahuan demensia masih rendah, dipengaruhi oleh usia, jenis kelamin, pendidikan, pendapatan, lokasi tinggal, dan pengalaman merawat. Stigma meningkatkan beban caregiver dan menurunkan kualitas perawatan.

Kata Kunci: Caregiver, Demensia, Literasi Kesehatan, Lansia

PENDAHULUAN

The increase in the number of older adults worldwide is a significant issue that warrants attention. This demographic shift is characterized not only by a growing population but also by a rise in health problems prevalent among the older adults. One of the most pressing issues is dementia, which can be defined as a progressive neurological disorder that significantly impacts the quality of life of affected individuals(Kimzey et al. 2022). The prevalence of dementia is increasing steadily, presenting a critical challenge for society (Kimzey et al. 2022).. Effective management of dementia requires a high level of health literacy and knowledge to prevent errors and facilitate early detection (Sie et al. 2023). Health literacy is defined as an individual's ability to seek, understand, and apply health information in daily , , which is essential for improving the quality of life for those people living with dementia (PLWD) (Sie et al. 2023).

Caregivers of individuals with dementia face numerous challenges, including daily care and decision-making, which can lead to emotional and physical stress (Warr et al. 2024). Research indicates that caregivers with higher health literacy are better equipped to manage these challenges due to their enhanced understanding of dementia-related information(Li et al. 2020). However, many caregivers report significant gaps in their knowledge and a lack of support from health service providers, exacerbating the caregiving burden (Kimzey et al. 2022).

Stigma surrounding dementia also plays a crucial role in shaping the quality of care provided(Parial et al. 2023). Currently, societal awareness of dementia remains relatively low, contributing to misconceptions and negative attitudes towards PLWD (Nkimbeng et al. 2024). Implementing educational programs within communities to enhance understanding of dementia can help reduce stigma and increase social support (Parial et al. 2023). Social stigma significantly impacts both people living with dementia (PLWD) and their caregivers. PLWD often experience social rejection, isolation, and internalized stigma, which worsens feelings of loneliness, depression, and reduces their quality of life. This stigma limits their social participation and access to healthcare services. Caregivers, on the other hand, face psychological stress, affiliate stigma, and social exclusion, which negatively affect their mental health and well-being. The stigma also contributes to increased caregiver burden, leading to depression and anxiety. To mitigate these effects, public awareness *campaigns, strong support systems, and dementia-friendly community initiatives are essential. These strategies can help reduce stigma, improve social inclusion, and enhance the well-being of both PLWD and caregivers (Jacobs et al. 2024).*

This study aims to determine characteristics of study related dementia literacy and knowledge about dementia among caregivers and community. By referencing previous, researchers hope to identify knowledge gaps related to dementia and effective strategies for enhancing health literacy in this area.

METODE

This scoping review was This scoping review was conducted following the guidelines for scoping reviews as outlined by (Levac, Colquhoun, and O'Brien 2010). The article search was carried out on December 28 2024, based on several databases.

Stage 1: Determine the Research Question

This research aimed to answer the question "What are the levels and determinants of health literacy and knowledge about dementia among caregivers and the community?"

Level 2: Search Strategy

This review involved searching multiple databases, including Scopus, PubMed, and ProQuest, on December 28, 2024 . The search utilized Boolean operators with the following keywords:

Stage 3: Data selection and process management data

This study selects data using specific criteria relevant to the research questions: The inclusion criteria are: (i) Articles published in English in full text form within the last 5 years (2019-2024). (ii) Individuals or groups who have a direct or indirect relationship with dementia, including family caregivers, informal caregivers, or the general public who are researched regarding knowledge or awareness about dementia. (iii) Studies addressing dementia-related health literacy, knowledge, or awareness. The exclusion criteria used are (i) Studies involving only professional health workers or those not relevant to dementia. (ii) Studies that focus on clinical or pharmacological interventions with no link to health literacy or knowledge.

From the total 335 articles identified through keyword searches, from Scopus (20), PubMed (6), and ProQuest (309). duplicates were checked using Mendeley, resulting in no duplicates found. After applying the inclusion and exclusion criteria, 250 articles were initially filtered out. Further review identified 85 articles that did not match the research question, leaving 20 full-text *articles for in-depth review. Ultimately, 13 articles were deemed unsuitable, resulting in 7 articles that were thoroughly reviewed in this study.*

Stage 4: Data Documentation

In this stage, data from the selected articles were documented in a structured table that included the following columns: author's name, year of publication and place location of the research, research objectives, study design, sample size, key findings, and limitations of each article. This structured documentation is crucial for the subsequent data extraction and analysis process.

Stage 5: Data Collection, Summarizing, and Compilation of the Final Report

This stage involved collecting and summarizing data using Microsoft Excel to organize findings from the 7 reviewed articles. Thematic analysis was conducted to identify and report key themes emerging from the data. This involved coding the data, grouping similar concepts, and interpreting the findings to draw meaningful conclusions relevant to health literacy and knowledge about dementia.

RESULT AND DISCUSSION

A total of 7 articles were included in this scoping review, comprising five quantitative studies and one qualitative study. The quantitative studies included cross-sectional design. The research was conducted across several countries, Italy, China, Saudi Arabia, Norway, Switzerland and the USA. The respondents in this study were caregivers and also the community who came from different backgrounds. The results of the studies are summarized in Table 2 (supplementary), which outlines the key findings from each article.

Table 3 (supplementary) presents the identified themes related to health literacy and knowledge of dementia. These themes include (i) low health literacy about dementia, (ii) varying levels of dementia knowledge, (iii) sociodemographic factors influencing understanding, (iv) stigma and perceptions surrounding dementia, and (v) challenges faced in caregiving.

Low Health Literacy about Dementia

Low dementia literacy has been identified in several studies, indicating that caregivers often lack the necessary understanding to provide proper care, which can result in inadequate or poor care for individuals with dementia (Lorini et al. 2023). For instance, caregivers may struggle to recognize symptoms or manage behavioral changes, leading to increased stress and frustration. Furthermore, individuals with low dementia literacy experience a higher caregiving burden when tasked with caring for or interacting with PLWD

(Häikiö, Cloutier, and Rugkåsa 2020; Lorini et al. 2023). This lack of health literacy can act as a boomerang for both caregivers and PLWD ultimately diminishing the quality of life for both parties (Al-Awad). Caregivers face significant emotional and physical stress due to their limited understanding, while dementia sufferers may receive inappropriate care as a result (Häikiö et al. 2020; Lorini et al. 2023).

Dementia Knowledge Level

Several articles discuss how the level of dementia knowledge is among respondent. Knowledge related to dementia encompasses understanding its symptoms (such as cognitive impairment and behavioral changes), causes (including Alzheimer's disease and vascular dementia), and risk factors (like age, genetics, and lifestyle)(Al-Awad et al. 2024; Ambriz et al. 2024; Häikiö et al. 2020; Nkimbeng et al. 2024). Research indicates that respondents with personal experience caring for elderly individuals with dementia—whether directly or indirectly—tend to have a higher level of knowledge compared to those without such experience (Pacifico et al. 2022; Ya-Jun et al. 2024). This highlights the importance of experiential learning in enhancing dementia literacy

Sociodemographic Factors

Demographic factors significantly influence the level of knowledge related to dementia among respondents. For example, younger respondents in several studies were found to have a higher level of knowledge regarding dementia; however, one study indicated that middle-aged to older adults exhibited better knowledge(Häikiö et al. 2020; Lorini et al. 2023; Pacifico et al. 2022). Additionally, geographic location plays a role, with individuals living in rural areas generally possessing lower levels of knowledge compared to those in urban settings(Al-Awad et al. 2024; Ya-Jun et al. 2024). Moreover, female respondents have been reported to have a better understanding of dementia than their male counterparts(Al-Awad et al. 2024; Pacifico et al. 2022). Factors such as income and education level also contribute to disparities in dementia literacy. Cultural influences are significant as well; individuals heavily influenced by local culture may exhibit lower levels of dementia literacy (Al-Awad et al. 2024). Understanding these sociodemographic factors is crucial for developing targeted public health strategies and educational programs aimed at improving dementia literacy.

Stigma and Perception

The stigma surrounding dementia is predominantly negative, stemming from misunderstandings and a lack of adequate *knowledge about the condition(Ambriz et al. 2024; Lorini et al. 2023). Many individuals report having never heard of dementia, which exacerbates negative attitudes and stigma within society. Cultural context plays a vital role in shaping these perceptions, as certain communities may have deeply ingrained beliefs about aging and cognitive decline(Al-Awad et al. 2024).*

Challenge

Challenges in disseminating education related to dementia arise from various factors, including limited access to treatment in health facilities, inadequate infrastructure, and financial constraints, particularly in underserved areas(Al-Awad et al. 2024; Pacifico et al. 2022). Additionally, geographic location can hinder timely access to care for elderly individuals with dementia. An individual's willingness to seek out information about dementia is also a critical factor; reluctance to pursue knowledge can lead to misunderstandings and perpetuate stigma(Al-Awad et al. 2024; Ya-Jun et al. 2024). To overcome these challenges, it is essential to implement community-based educational initiatives that improve access to information and resources related to dementia care.

Discussion

This scoping review aims to determine characteristic of study related dementia literacy and knowledge of dementia related to dementia among caregivers and community. The findings indicate that health literacy in the general public remains low, hindering individuals' ability to accept, interpret, and act upon information related to dementia cognitive decline (Al-Awad et al. 2024). This low health literacy and knowledge, recognized as a significant global issue, adversely affect individuals' capacity to manage and seek appropriate care for PLWD (Ali et al. 2023). The findings suggest that low health literacy remains a global challenge, limiting the ability to manage and seek care for people living with dementia (PLWD). Factors such as age, gender, prior caregiving experience, income, and geographic location contribute to disparities in dementia-related knowledge. Additionally, the paper highlights the pervasive negative stigma associated with dementia, which exacerbates emotional and physical stress among caregivers and leads to inadequate care for PLWD (Warr et al. 2024). The query highlights both negative and positive tendencies regarding the identification of widespread low health literacy and stigma in dementia care. Here *is a detailed summary addressing both aspects:*

Negative Tendency: Barriers to Effective Dementia Care

Low Health Literacy and Stigma: Stigma associated with dementia significantly impacts the quality of life for people living with dementia (PLWD) and their caregivers. It creates barriers to timely diagnosis, treatment, and comprehensive support (Aboseif and Woo 2020). Stigma can be public, professional, structural, self-stigma, or family stigma, each with specific characteristics and consequences (Aboseif and Woo 2020).

Impact on Care: Stigma and low health literacy lead to social exclusion, delayed diagnoses, and poor access to resources, which in turn affect the readiness of communities to support PLWD and their caregivers. This can result in a pessimistic outlook on the community's ability to provide adequate support.

Positive Tendency: Importance of Interventions

1. ***Caregiver Training and Support**: Interventions such as the modified New York University Caregiver Intervention (NYUCI) have shown significant improvements in caregiver well-being, reducing symptoms of depression and caregiver burden (Sperling et al. 2020). These interventions include dementia education, coping skills, behavioral management training, and emotional support.*
2. ***Health Education**: Enhancing dementia literacy is crucial for early diagnosis and proper management. Studies indicate that increasing public awareness and knowledge about dementia can improve community inclusiveness and support for PLWD (Parkinson, Sullivan, and Graham 2022).*
3. ***Stigma Reduction Initiatives**: Research-based drama and other public health strategies have been effective in reducing stigma, fostering critical reflection, and promoting inclusive engagement of PLWD (Kontos et al. 2020). Tailored, culturally appropriate interventions are also necessary to address stigma within diverse communities.*
4. ***Psychosocial Interventions**: These interventions improve cognitive abilities, emotional well-being, and reduce behavioral symptoms in PLWD. They also support family caregivers through educational groups and support programs, complementing pharmacological treatments(Sperling et al. 2020).*

Factors influencing an individual's knowledge of dementia include age, *gender, prior care experience, education level, income, and geographic location(Al-Awad et al. 2024). In men, individuals with low incomes, and those lacking prior care experience tend to have lower levels of dementia-related knowledge, creating disparities among groups(Akyol et al. 2024). This scoping review highlights critical challenges in dementia literacy among caregivers and the general public, including low health literacy, widespread stigma, and disparities in knowledge influenced by factors like age, gender, income, and caregiving experience. Low health literacy limits individuals' ability to manage dementia care, while stigma leads to social isolation, delayed diagnoses, and inadequate support for people living with dementia (PLWD) and their caregivers (Maximiano-Barreto et al. 2024). However, opportunities for improvement include health education to enhance awareness, caregiver training programs to reduce burden, and stigma reduction initiatives to foster inclusivity. Addressing these issues is essential to improving care and outcomes for PLWD, particularly as the aging population grows (Lo 2020).*

Limited dementia knowledge, influenced by factors such as age, gender, income, education, and caregiving experience, creates significant disparities in understanding and managing the condition (Van Patten and Tremont 2018). Low health literacy and pervasive stigma further exacerbate these challenges, leading to delayed diagnoses, inadequate care, and emotional stress for both people living with dementia (PLWD) and their caregivers. However, the review also identifies promising solutions, including public health education to raise awareness, caregiver training programs to enhance skills and reduce burden, and stigma reduction initiatives to foster inclusivity. Addressing these gaps is essential to improving dementia care and creating supportive environments for PLWD and their caregivers (Andrews et al. 2024).Consequently, caregivers experience significant emotional and physical stress due to this stigma and lack of support, highlighting the urgent need for comprehensive support services, caregiver training, and health education initiatives focused on dementia awareness(Hu et al. 2024; Laparidou et al. 2019).

This scoping review highlights the global challenges of low dementia literacy, pervasive stigma, and disparities in knowledge influenced by factors like age, gender, and income. It emphasizes the negative impacts on timely diagnosis, care, and caregiver well-being while identifying novel solutions, including health education, caregiver training, and *stigma reduction initiatives. These findings underscore the urgency of improving dementia awareness and support systems, particularly as the aging population grows. Future research should develop targeted interventions to improve dementia literacy and reduce stigma, focusing on underserved populations. Studies should explore demographic influences on dementia knowledge and evaluate culturally relevant education programs and digital tools. Creating robust measurement tools and assessing intervention outcomes are essential for advancing dementia care.*

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CONCLUSSION

Most people still have low health literacy and knowledge about dementia. Caregivers with prior experience tend to be more knowledgeable. Factors such as age, gender, education, income, and location affect knowledge levels. Stigma delays diagnosis and increases caregiver burden. Improving information access and addressing stigma should be priorities for future research and public health efforts.

RECOMMENDATION

Future efforts should focus on increasing dementia literacy through accessible community education and caregiver training. Anti stigma campaigns are essential to promote early diagnosis and reduce caregiving burden. Further research is needed to evaluate effective strategies for knowledge improvement and stigma reduction.

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