


Understanding Practices and Support Needs of Family Caregivers of People with Dementia in Africa: A Scoping Review Protocol



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ABSTRACT

Extant literature has reported the challenges and stressors caregivers of people with dementia face globally. Local realities and contexts often shape these challenges. For example, in regions of Africa where the prevalence of caregiving is increasing, beliefs about dementia and limited infrastructures create unique challenges for caregivers, potentially restricting caregivers' capacities. Yet directions for policy, practice, and research are often informed by research conducted in regions outside of Africa or fail to account for local contexts. This scoping review seeks to understand the knowledge base on regional differences and similarities in the experiences of caregivers supporting persons with dementia in the region of Africa. The review will be guided by Arksey and O'Malley's five-stage- framework. Five databases: Ageline, MEDLINE, Social Science Abstract, Psych-Info, and African-wide information will be searched. Citations from these databases will be subjected to two levels of screening The Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) will describe and document the inclusion and exclusion process. This scoping review will improve our understanding of unique practices and pressures experienced by caregivers of persons with dementia in different localities in Africa. It will also identify support needs and knowledge gaps in African region.

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INTRODUCTION

Dementia is a public health concern, with over 50 million individuals affected worldwide.¹ The African Consortium on Dementia reported a 400+% increase in the prevalence of dementia in the region (from 2.3% in 1995 to 20% in 2019) While dementia rates are not always reported in Africa, this condition is still recognized as one that carries the most significant significant disease burden among older adults in the region.² Family caregivers are amongst those most severely affected by these growing prevalence rates. This is because care infrastructures are scarce, cultural expectations to provide care persist, and

¹ Serge Gauthier et al., *World Alzheimer Report 2022* (London: Alzheimer's Disease International, 2022), <https://www.alzint.org/u/World-Alzheimer-Report-2022.pdf>.

² World Health Organization, *Global Action Plan on the Public Health Response to Dementia 2017–2025* (Geneva: World Health Organization, 2017), <https://iris.who.int/handle/10665/259615>; Gauthier et al., *World Alzheimer Report 2022*.

the stigma associated with dementia makes help-seeking complex in some parts of the region.³ These local realities and contextual factors shape caregivers' experiences supporting persons with dementia, and caregiving practices. Despite the growing recognition of the significance of caregiving for individuals with dementia, there remains a limited understanding of the specific challenges and experiences faced by caregivers in the African region, which needs to be explored.

Africa, a continent of 54 countries, includes a myriad of divergent local realities.⁴ Within this rich tapestry, there exists considerable variation in caregiving practices, societal norms, and available resources, all of which profoundly shape the experiences of caregivers supporting individuals with dementia. Yet to date, little has been done to identify the differences and similarities in providing care to persons with dementia in different parts of the continent. Investigating these differences and similarities will shed light on the unique challenges faced by caregivers and the factors that contribute to successful caregiving experiences. Further, many of the reviews that do exist focus on risk factors and prevention strategies for acquiring dementia.⁵ Three scoping reviews have recently been published to understand the experiences of caring for persons with dementia in Africa.⁶

While these reviews provide a glimpse into caregivers' needs and experiences supporting persons with dementia, two reviews focused specifically on Sub-Saharan Africa, using limited search terms and databases⁷ and one focused on health professionals' perspectives in North Africa.⁸ Hence a comprehensive scoping review was considered a first step towards understanding differences in caregivers' experiences and challenges across regions of Africa by using a robust search terms and a broad range of databases which has not been conducted. This proposed review will fill these gaps and, by so doing, offer important directions for future policy, practice, and research.

METHODOLOGY

This proposed scoping review will be guided by Arksey and O'Malley's five-stage York framework which consists of (1) identifying the research question, (2) locating relevant studies; (3) selecting studies; (4) charting the data; (5) collating, summarizing, and reporting the results.⁹ Utilizing this framework will help the researchers articulate the current state of knowledge and identify gaps in the field.¹⁰ This scoping review has been registered with the Open Science Framework.¹¹ Stages one through three are near completion.

³ Naana Agyeman et al., "When Someone Becomes Old Then Every Part of the Body Too Becomes Old": Experiences of Living with Dementia in Kintampo, Rural Ghana," *Transcultural Psychiatry* 56, no. 5 (October 2, 2019): 895–917, <https://doi.org/10.1177/1363461519847054>; C L Dotchin and R W Walker, "The Prevalence of Essential Tremor in Rural Northern Tanzania," *Journal of Neurology, Neurosurgery & Psychiatry* 79, no. 10 (October 1, 2008): 1107–9, <https://doi.org/10.1136/jnnp.2007.134304>; Abeedah Hendricks-Lalla and Chrisma Pretorius, "The Male Familial Caregiver Experience of Caring for Persons with Alzheimer's Disease from Low Socio-Economic Status: A South African Perspective," *Dementia* 19, no. 3 (April 18, 2020): 618–39, <https://doi.org/10.1177/1471301218781372>; Flora Mkhonto and Ingrid Hanssen, "When People with Dementia Are Perceived as Witches. Consequences for Patients and Nurse Education in South Africa," *Journal of Clinical Nursing* 27, no. 1–2 (January 20, 2018), <https://doi.org/10.1111/jocn.13909>; Declare Mushi et al., "Social Representation and Practices Related to Dementia in Hai District of Tanzania," *BMC Public Health* 14, no. 1 (December 19, 2014): 260, <https://doi.org/10.1186/1471-2458-14-260>.

⁴ "World Population Review," 2023, <https://worldpopulationreview.com/>.

⁵ Rufus O. Akinyemi et al., "Dementia in Africa: Current Evidence, Knowledge Gaps, and Future Directions," *Alzheimer's & Dementia* 18, no. 4 (April 27, 2022): 790–809, <https://doi.org/10.1002/alz.12432>; Davies Adeloye et al., "Prevalence of Dementia in Nigeria: A Systematic Review of the Evidence," *Journal of Global Health Reports* 3 (March 10, 2019), <https://doi.org/10.29392/jogh.3.e2019014>.

⁶ Isaac A Adedeji et al., "Experiences and Practices of Caregiving for Older Persons Living with Dementia in African Countries: A Qualitative Scoping Review," *Dementia* 21, no. 3 (April 3, 2022): 995–1011, <https://doi.org/10.1177/14713012211065398>; Tanya Kane et al., "Dementia Caregiving in the Middle East and North Africa: A Scoping Review," *Transcultural Psychiatry* 58, no. 6 (December 19, 2021): 844–58, <https://doi.org/10.1177/13634615211036404>; Purity Mwendwa et al., "A Systematic Review and Narrative Synthesis of the Experiences with Caring for Older People Living with Dementia in Sub-Saharan Africa," *BMC Geriatrics* 22, no. 1 (December 13, 2022): 961, <https://doi.org/10.1186/s12877-022-03668-2>.

⁷ Adedeji et al., "Experiences and Practices of Caregiving for Older Persons Living with Dementia in African Countries: A Qualitative Scoping Review"; Kane et al., "Dementia Caregiving in the Middle East and North Africa: A Scoping Review"; Mwendwa et al., "A Systematic Review and Narrative Synthesis of the Experiences with Caring for Older People Living with Dementia in Sub-Saharan Africa."

⁸ Kane et al., "Dementia Caregiving in the Middle East and North Africa: A Scoping Review."

⁹ Arksey and O'Malley, "Scoping Studies: Towards a Methodological Framework."

¹⁰ Arksey and O'Malley, "Scoping Studies: Towards a Methodological Framework."

¹¹ Oluwagbemiga Oyinlola and Tamara Sussman, "Practices and Support Needs of Family Caregivers of People with Dementia in Africa Dementia Caregiving Practices in Africa," *OSF Registers*, June 5, 2023.

Stage 1: Identifying the research question(s)

The following research questions, which have been developed and refined by the authors, will guide the proposed scoping review. What does the current state of knowledge tell about:-

- a. the impact of stigma on families caring for people with dementia in different regions of Africa.
- b. the use of formal versus informal support for caregivers of people with dementia in different regions of Africa?
- c. positive experiences of caregivers supporting people with dementia in different regions of Africa?

Stage 2: Identification of relevant studies

The researchers will thoroughly search all retrievable studies and hand-search journals to determine the best available evidence. The reference lists from prior related reviews and included studies will be reviewed for potential studies. A forward citation search will be conducted using Google Scholar for studies citing our included studies. There are no date, language, or location restrictions on the searches. The review will search five electronic databases: AgeLine, MEDLINE, Social Science Abstracts, PsychInfo, and African-wide information. The inclusion of African-wide is critical to ensure a robust review of the literature as most African-based journals are not indexed in major databases more typically used for scoping reviews of this nature. (see Table 1 for Key terms). Hand-searching of the reference lists and citations will be included in sources to identify further studies for inclusion in the review. Google Scholar (scholar.google.ca) will be used for finding citing references for possible inclusion in the review, this is to ensure that no relevant articles have been overlooked.

Table 1: Key Search Terms

Concepts	Key terms
Dementia	“Dementia” OR “Mild cognitive impairment (MCI)” OR “Cognitive decline” OR “Cognitive impairment” OR “Memory loss” OR “Neurodegenerative disease” OR “Age-related cognitive decline” OR “Alzheimer's disease”
Family caregivers	“Family caregivers” OR “Informal caregivers” OR “Care partners” OR “Family members” OR “Spouses” OR “Adult children” OR “Support systems” OR “Family dynamic” OR “Family relationships” OR “Caregiving roles” OR “caregiving experience”
Caregiving practices	“Caregivers” OR “Caregiver burden” OR “Caregiver intervention” OR “Caregiver challenges” OR “Caregiver policies” OR “Community-based care” OR “Home care”
Support needs	“Support needs” OR “Caregiver burden” OR “Coping strategies” OR “Social support” OR “Emotional support” OR “Practical support” OR “Financial support” OR “Respite care” OR “Caregiver education” OR “Training programs” OR “Interventions” OR “Telehealth” OR “Community-based care” OR “Home care” OR “Daycare” OR “Memory clinics” OR “Caregiver assessment” OR “Quality of life”
Africa	exp Africa/ or (Africa* or Algeria or Angola or Benin or Botswana or "Burkina Faso" or Burundi or "Cabo Verde" or "Cape Verde" or Cameroon or Central African Republic or Chad or Comoros or Congo or "Cote d'Ivoire" or "Ivory Coast" or Djibouti or Egypt or "Equatorial Guinea" or Eritrea or Eswatini or Ethiopia or Gabon or Gambia or Ghana or Guinea or "Guinea-Bissau" or Kenya or Lesotho or Liberia or Libya or Madagascar or Malawi or Mali or Mauritania or Mauritius or Morocco or Mozambique or Namibia or Niger or Nigeria or "Nile Valley" or Rwanda or "Sao Tome" or Principe or Senegal or Seychelles or "Sierra Leone" or Somalia or "South Africa" or "Sub Saharan" or Sudan or Tanzania or Togo or Tunisia or Uganda or Zambia or Zimbabwe).mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol

	supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]
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The author(s) will be contacted three times when full text cannot be located, and articles whose author(s) do not respond on the third attempt will be excluded from the review. There will be no year restriction on the article to be included during database searches. Therefore, the database will be searched from inception till 2023. Authors will hand-search references of all the screened articles to ensure that no relevant articles are overlooked.

Stage 3: Selecting studies

All the article citations from the above databases will be exported into Ryann QCRi version 12 to facilitate the removal of duplicates and study screening. The selection will be conducted in two stages: 1) the title/abstract and 2) full-text screening. At each stage of screening, two independent authors will independently conduct the articles' title/abstract and full-text screening following pre-determined inclusion and exclusion criteria as shown in Table 2. If there are discrepancies at any stage, the two reviewers and the last author will meet to discuss and address them. The rationale for the exclusion of studies will be documented, and the selection process of studies will be presented in a flowchart.

Table 2: Inclusion and Exclusion Criteria

Inclusion criteria	Exclusion criteria
Peer-reviewed studies	Published books, conference papers, grey literature
Written in English	Studies conducted in languages other than English
Accessible full-text papers	Theses and dissertation
Studies that focused on caregiver's experiences supporting people with dementia	Grey literature, opinion pieces, and reviews
Studies conducted in Africa	
Empirical studies (qualitative, quantitative, mixed-Methods)	

Stage 4: Data collection and charting

This scoping review will utilize a standardized Microsoft Excel data-charting form which will be used to chart the data. The following information will be extracted from the included studies: author name(s), year of publication, country the study was conducted, aims/research questions/hypothesis, study settings, type of study (qualitative, quantitative, or mixed-method), study design, sampling method, participants characteristics (e.g., the number of participants, mean age of the participants, sex/gender), study themes (if qualitative), study findings (if quantitative or mixed-method), study setting (rural or urban settings) and policy implications. Two reviewers will independently perform a pilot data extraction, meet, and discuss any discrepancies. A third reviewer will be consulted if there is any persistent disagreement.

Stage 5: Collection, summarising, and reporting the results

All authors will participate in the analysis and summary of key findings based on extracted data. We expect this to be an iterative process involving the initial identification of descriptive themes followed by the co-development of interpretative themes that appear to best capture key findings and gaps. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) will be used as a reporting guideline.¹² While it is impossible to predetermine the best method of reporting the thematic results, we intend to present the results using the combination of narrative and visual (map, diagram, or table) methods.

¹² Andrea C. Tricco et al., "PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation," *Annals of Internal Medicine* 169, no. 7 (October 2, 2018): 467–73, <https://doi.org/10.7326/M18-0850>.

Ethics and Dissemination

Ethical approval is not necessary because this study will be based on existing published results. The final report of this study will be in this journal after a peer-review of scientific journals.

RESULTS

This scoping review is expected to be completed within 6 months of the protocol's release. The findings will be presented in the framework described above.

DISCUSSION

There is a small but growing literature on caregivers' experiences supporting persons with dementia in different regions of Africa. Findings from this literature require further analysis so that gaps can be identified and more targeted research capturing the regional differences and similarities that shape the caregiving experiences of people with dementia in different parts of Africa can be highlighted. Synthesizing this literature may also reveal policy and practice gaps that, if addressed, could improve the circumstances of the growing number of caregivers of persons with dementia spread across the region. This could help reduce stigma and increase understanding of the importance of supporting caregivers in providing dementia care.

COMPETING INTERESTS

The authors declare no competing interests.

AUTHOR ROLES

OO conceived the project, OO, TS, AI designed the study, OO did preliminary searches on MEDLINE, screening, and review; OO and AI did Google Scholar searches, screening, and review. All authors read and approved the manuscript for publication.

GRANT INFORMATION

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- Mkhonto, Flora, and Ingrid Hanssen. "When People with Dementia Are Perceived as Witches. Consequences for Patients and Nurse Education in South Africa." *Journal of Clinical Nursing* 27, no. 1–2 (January 20, 2018). <https://doi.org/10.1111/jocn.13909>.
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APPENDIX**Preliminary Search Strategy from MEDLINE****OVID MEDLINE® All <1946 to October 12, 2023**

S/N		
1	("Dementia" or "Mild cognitive impairment (MCI)" or "Cognitiv* decline" or "Cognitive impairment" or "Memory loss" or "Neurodegenerative disease" or "Age-related cognitive decline" or "Alzheimer's disease").mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]	350666
2	("Families caregivers or Informal caregiv*" or "Care partners" or "Family members" or "Spouses" or "Adult children" or "Support systems" or "Family dynamic" or "Family relationships" or "Caregiving roles" or "caregiving experience").mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]	138654
3	("Caregiving OR Caregiver burden OR Caregiver intervention OR Caregiver challenges OR Caregiver policies" or home care).mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]	55832
4	("Support needs" or "Caregiver burden" or "Coping strategies" or "Social support" or "Emotional support" or "Practical support" or "Financial support" or "Respite care" or "Caregiver education" or "Training programs" or "Interventions" or "Telehealth" or "Community-based care" or "Home care" or "Daycare" or "Memory clinics" or "Caregiver assessment" or "Quality of life").mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]	1242594
5	exp Africa/ or (Africa* or Algeria or Angola or Benin or Botswana or "Burkina Faso" or Burundi or "Cabo Verde" or "Cape Verde" or Cameroon or Central African Republic or Chad or Comoros or Congo or "Cote d'Ivoire" or "Ivory Coast" or Djibouti or Egypt or "Equatorial Guinea" or Eritrea or Eswatini or Ethiopia or Gabon or Gambia or Ghana or Guinea or "Guinea-Bissau" or Kenya or Lesotho or Liberia or Libya or Madagascar or Malawi or Mali or Mauritania or Mauritius or Morocco or Mozambique or Namibia or Niger or Nigeria or "Nile Valley" or Rwanda or "Sao Tome" or Principe or Senegal or Seychelles or "Sierra Leone" or Somalia or "South Africa" or "Sub Saharan" or Sudan or Tanzania or Togo or Tunisia or Uganda or Zambia or Zimbabwe).mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary	782668

	concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]	
6	1 and 2	5181
7	3 and 4 and 5	1238
8	6 and 7	945
9	1 and 2 and 3 and 4 and 5	421