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# SUPPORTING FAMILY CAREGIVERS IN PROVIDING CARE

*A Scoping Review of the experiences of family caregivers of older adults with chronic illness*

This paper is part of my research at the University of West London, serving as an opportunity and platform to promote the wellbeing and quality of life for family caregivers. A Scoping Review of contemporary literature reveals a looming ageing population with chronic health conditions, shortages of formal care providers in developing societies and inadequate support to caregivers (Faronbi, Ajadi & Gobbens, 2020). Most of the reviewed studies base their research on single chronic diseases in older people, which ignores the overall, combined effect of the caregiver's burden regarding older adults with multiple chronic diseases. Conceptual clarity on caregivers' experiences of multiple chronic conditions amongst older people is lacking. In this paper, I make a case for further research on the experience of family caregivers of older adults with multi-chronic conditions. Moreover, I argue for a need to investigate the perception of policy implementation at all levels on the support for this group within a given society. Overall, my research is socially relevant in promoting support for the informal care sector, among other, in Nigeria.

## Population ageing

Globally, there were 703 million people aged 65 or over in 2019. Over the coming three decades, the global number of older people is projected to more than double, reaching over 1.5 billion in 2050 (United Nations Department of Economic and Social Affairs, 2020). Nigeria, like any other country in Sub-Saharan Africa, sees this emerging issue as a serious challenge for its future. Currently, about 8% of Nigerians are aged 60 or older, which constitutes a total of about 10 million people. Survey reports and demographic estimations have evidenced an increase in both the absolute number and proportion of older adults in Nigeria. From 4.6 million in 1991, to 8.8 million in 2012; and it is estimated to increase further to 11.5 million in 2025; and 25.5 million in 2050 (Dokpesi, 2017).

## The realities of informal caregiving

A growing proportion of older people globally has contributed to a shift from institutional to community care. As a result, older adults are increasingly depending on their families for support with daily activities. Consequently, the number of family caregivers, also known as informal caregivers, has been steadily rising. In the United States, it is estimated that there are 65.7 million unpaid family caregivers. A similar situation can be observed in the UK, with an estimated 6.5 million informal caregivers currently looking after older members of their families. The estimated economic value of their unpaid labour amounts to USD 470 billion and £119 billion respectively (Phillips, 2019).

These examples show the important, even vital role of family caregiving within the healthcare sector. The realities of informal caregiving in these rapidly ageing western societies could serve as examples that help other societies, like Nigeria, to prepare their informal care sector for an ageing population. According to various studies, the traditional system of family support appears to care for the increasing number of older people in Nigeria. The task of caring in Nigeria is traditionally reserved for females, who assist care recipients with Activities of Daily Living (ADL). The economic value of this system of family support in Nigeria is not clear, as studies are unavailable in the country regarding the socioeconomic costs of caring for dependent older people (Mudrazija, 2019).

## Research objectives

This paper has three research objectives, namely to:

- i. identify relevant literature on the experience of family caregivers for older adults with chronic illness;
- ii. generate themes based on study objective(s); and
- iii. generate research questions for each theme, addressing gaps in the existing literature.





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### Methodology

A Scoping Review was undertaken to synthesise current literature. This is a newer reviewing type, with the aim of mapping key concepts that underpin a research area and identifying the nature of and gaps in existing knowledge so as to provide a basis for further research. Unlike a Systematic Literature Review, Scoping Reviews include broader literature sources. These may include a range of relevant databases, grey literature and attempts to identify unpublished literature (Tricco et al., 2018). Due to the wide variability of studies in relation to study design, population, types of intervention and outcomes, the author decided that a Narrative Synthesis constitutes the best tool for synthesising the findings of the different studies included in the review. The reference management software RefWorks (Cite Them Right – Harvard) was used to organise and store all the literature. A Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart (see Figure 1), obtained from Moher and colleagues (2009), summarises the review process. Search terms were generated using the modified Population, Context and Outcome (PCO) framework (Riesenberg & Justice, 2014).

### Selection of sources of evidence

The review of literature was undertaken through advanced searches of academic databases and grey literature, using a pre-defined set of key words. The literature search strategy was primarily developed for advanced searching, using five data base sources: Academic Search Elite, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Science Direct and Medical Literature Analysis and Retrieval System Online (MEDLINE) and UWL's Summon. The search was carried out using the 'OR' Boolean operator as a single group. Each single group was then combined using the 'AND' function to produce a list of citations. Searches using the term 'family caregivers' were subsequently combined with keywords such as 'elderly', 'chronic illness', 'support', 'care burden', and 'coping', so as to narrow down the range of results. This search protocol was subsequently replicated with other search engines and databases, as well as grey literature sources, reference lists and citations of all relevant papers. This ensured an optimal identification and location of relevant sources. The limits applied

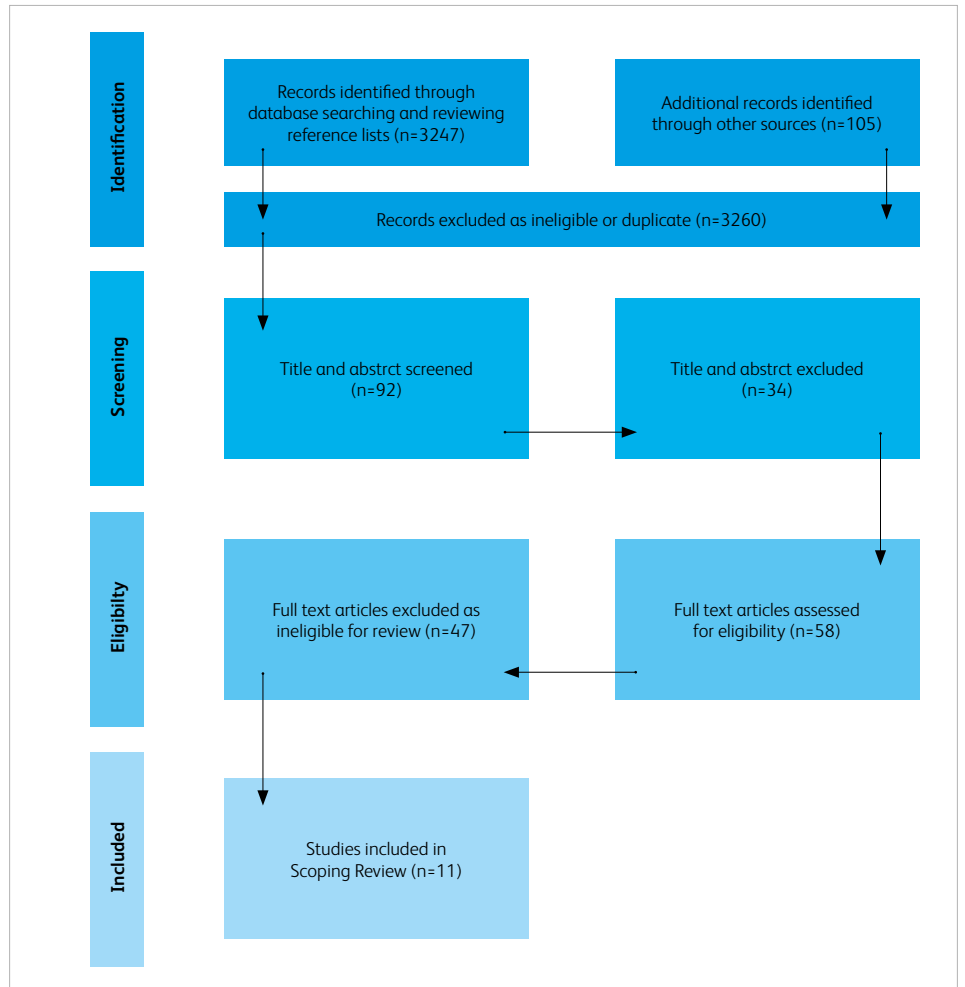


FIGURE 1 Scoping Review Process

to searches for work in English only, involving participants aged 60 years and older, peer reviewed full-text articles, and published between 1 July 2011 and 31 July 2021. Articles that did not provide a comprehensive understanding of the experience of family caregivers of older adults with chronic illness, but focused more broadly on family caregiving, were excluded. All literature searches took place between October 2020 to July 2021.

### Findings

3,352 records were initially identified throughout all databases. The results were narrowed down to peer reviewed articles, of which titles and abstracts were reviewed for eligibility. Subsequently, full-text articles were assessed and included only if they 1) focused exclusively on family caregiver experiences with adults aged 60 and older with chronic illness, and 2) were published in English within the last 10 years on electronic databases. After reviewing the full text, a total of 11 articles were included in the literature review (see Figure 1). A final search of databases was conducted to ensure that all relevant literature had been captured. The literature review was considered complete when the same articles began to appear repeatedly in the electronic searches.

*Unlike a Systematic Literature Review, Scoping Reviews include broader literature sources. These may include a range of relevant databases, grey literature and attempts to identify unpublished literature*



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### Themes

A recognition of the positive aspects of family caregiving was evident in the literature reviewed—with an emphasis on a heightened sense of responsibility, improved relationships with care recipients, increased level of patience, and sense of reward. However, the harsh realities of caregiving as experienced by unpaid family members, friends, and neighbours was also apparent, when it came to the burden of care, coping mechanism and support needed.

#### Theme 1: Burden and coping

Caregivers of older adults with chronic illnesses are fully exposed to the burden associated with their caregiving activities. As a result, caregivers experience stressors while carrying out their caregiving activities. Significant stress, due to financial instability, emotional strain, and physical support with Activities of Daily Living, are all part of the dynamics that play out in a caregiving role. However, the concept of burden used in research so far, lacks a consistent conceptualisation and operational definition. Critical attributes of burden include subjective perceptions, multidimensional phenomena, dynamic changes, and overload. Therefore, it is important to identify the different sources of burden and provide directions for caregiver intervention (Sit et al., 2020).

Most of the reviewed studies base their research on the family caregiving burden of single chronic conditions, such as cancer, diabetes, dementia, Parkinson's, or stroke. Some studies investigate the diversity of experiences of family caregivers of older adults with multiple chronic conditions. However, there is no literature at all from Benue State, Nigeria, on the experience of family caregivers of older people with a multiple chronic condition. This Scoping Review therefore identified the following research question: What are the challenges and coping mechanisms associated with informal caregiving of older adults with (multiple) chronic illnesses?

#### Theme 2: Support and intervention

There is increasing attention in research, as well as in government policy, on the support of family carers. However, supporting family carers may prove to be a more complex endeavour than one might initially believe. Within the nursing literature, caregiver support has been defined as the provision of general tangibles, such as information, education, economic aid, goods, and external services. Some researchers suggest that support measures, such as information sharing, training, and practical support, are crucial for sustaining family caregiving (Lilly et al., 2012). By contrast, a meta-review of international studies on family caregiver support interventions found no evidence of improvements regarding family caregiver stress, burden, psychological well-being, or quality of life based on the above support measures. There is a diversity of information as to how family caregivers of older people should best be supported, leading to various interpretations as to how support is and should be measured and operationalised. The following question then arises: How can caregivers be supported optimally?

#### Theme 3: Support delivery system

Given the invaluable role of informal care, the need to support family caregivers cannot be overemphasised. It spans from caregivers' need for sustainable support and resilience, to using their experience to inform interventions and raise awareness about the importance of providing support and resources at multiple levels—local, state, and national. Furthermore, understanding how these needs can impact on the delivery of support interventions and assist in developing a model of care for family caregivers, is fundamental (Parkinson et al., 2017).

For interventions to be successful, attention should be paid to the way in which policy implementation interacts and engages with caregivers. Supportive interactions are shown to have a positive impact on caregiver perceptions, decision making and coping. To work well with family caregivers, a partnership approach—that is, working with family caregivers of older people suffering from chronic illness, in order to assess their specific support needs—is recommended. Working in partnership with caregivers is a core principle in the policy rhetoric. For interventions to be effective, caregivers need to trust the people providing support services, see them as valuable and perceive the intervention as related to their needs (Lambert & Gargis, 2017). Furthermore, the absence of family caregiver support could be associated with a lack of awareness regarding the experiences of family caregivers. The notion of family caregiver support policy at all levels, paves the way for further investigating perceptions of policy implementation with respect to support for family caregiving (Cho & Kim, 2016). This gives rise to the final research question: What are the perceptions of those implementing policy in terms of family caregiving?



*Researchers argue that, as the ageing population increases, the demand for informal caregiving is becoming an ever more important concern for researchers and policy makers alike*

### Conclusion

Understanding the themes from this Scoping Review reveals a growing body of knowledge on the experiences of family caregivers. This review of relevant literature shows how family caregivers caring for older people with chronic illnesses are heavily exposed to the burden generally associated with their caregiving activities and their coping mechanisms. The review also reveals some diverse interventions already in place to support family caregivers. Lastly, the Scoping Review encourages a discussion on how to best engage and support family caregivers at local, state, and national levels of policy implementation. Researchers argue that, as the ageing population increases, the demand for informal caregiving is becoming an ever more important concern for researchers and policy makers alike. Also, the steady increase in the number of people suffering from chronic diseases imposes new demands on healthcare and, at the same time, the need for informal caregivers is increasing. Therefore, this scenario clearly requires special attention in addressing the issue of an informal caregiving sector.

Why is this such an issue? And why is it important to conduct further research on this phenomenon? Family caregivers are the backbone of the healthcare system. Over time, caregiving can take a tremendous toll on the caregiver. Therefore, support from family, friends and, most importantly, the government, is required. My PhD research aims to explore family carer burdens, coping mechanisms, and support delivery systems. Although there is a great deal of writing about, and research into family caregiver experiences with older adults who have single chronic conditions, there is very little discussion on the experience of carers of older adults with multiple chronic conditions.

Considering the rising importance of family caregiving, it is surprising that it has attracted little scholarly attention globally so far. However, this could be explained by the fact that countries lack an awareness of and evidence on the lived experiences of family caregivers. The identification of appropriate family caregiver interventions is thus important for future policy practice for various reasons. Firstly, a greater emphasis on providing support for family caregivers in developing societies will mitigate the burden of caregiving. Secondly, family caregivers and care recipient quality of life will be positively affected. Finally, family caregivers of older adults with chronic illnesses can be an asset to the healthcare sector, especially if adequate support is provided to them. Hence, consideration should be given to the potential merits of officially recognising the true worth and value of family carers within the healthcare system.

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### Keywords

Family caregivers, older adults, chronic illness, care burden, caregiver support

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