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a scoping review

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**Exploring Experiences of Family Caregivers for older adults with Chronic Illness:  
A Scoping Review**

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## **Abstract**

A Scoping Review was conducted to explore key issues that underpin the experiences of family caregivers of older adults with chronic illness. The review aims to identify the gap in literature and synthesise evidence on this topic. Globally, family caregivers of older adults with chronic illness experience burden. Evidence suggests that family caregivers' needs are poorly understood and remain largely under recognised by healthcare services. Moreover, little is known about the experience of family caregivers caring for older adults with multiple chronic conditions. Data bases used included: Academic Search Elite, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Science Direct, SCOPUS, MEDLINE, and grey literature. 3352 records were identified, 58 full-text articles were assessed for eligibility, and 11 papers included in the literature review. Data are narratively synthesized. This review provides findings that suggest further research.

## **Keywords**

Caregivers, older adults, chronic illness, caregiver burden, family, support

## **Introduction**

The world's population is ageing with an increased prevalence of chronic long-term conditions, for which there is currently no cure, but managed with drugs <sup>1</sup>. These conditions can include dementia, cancer, diabetes, arthritis, heart disease, and stroke. Globally, there were 703 million older persons aged 65 or over in 2019. The global number of older persons is projected to more than double, reaching over 1.5 billion persons in 2050 <sup>2</sup>. The Sub-Saharan region with the smallest proportion of the elderly is projected to see the size of the elderly grow by 2.3 times between 2000 and 2030 (UNDESA, 2015). Consequently, as the ageing population increases, the demand for informal caregiving is becoming an ever more important concern for

researchers and policy makers alike (Bauer and Sousa-Poza, 2015). Also, the steady increase in the number of people suffering from chronic diseases raises new demands on healthcare, while also, the need for informal caregivers. A growing proportion of elders globally has contributed to a shift from institutional to community care. Elders 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).

Family caregivers are recognised as the backbone of the health care system <sup>3</sup>. They play an essential role in caring for older adults suffering from chronic illnesses <sup>4</sup>. Family caregivers are unpaid family members or significant persons who provide practical support at given times for an ill or aged relative who cannot perform a variety of essential tasks <sup>5</sup>. Family caregiving can be deeply satisfying as family members can be drawn to develop a closer relationship that perhaps never existed. However, as the demands increase physically, emotionally, and cognitively for the care recipient, the family caregiver also experiences a decline in physical function, increased psychological distress and financial stress. This manuscript uses a scoping review to answer the researchers' questions concerning the burden, coping and support delivery system of family caregivers of older adults with chronic disease. Numerous studies report that caregiving for older adults with single chronic conditions places a considerable burden on family caregivers. However, very few studies have focused on the experience of family caregivers of older adults with multiple chronic conditions. Older adults with chronic disease often have multiple comorbidities that make caregiving complex and highly demanding. Thus, to fill this gap, it is important to first and foremost show evidence, then to further investigate

the experience of family caregivers of older adults with multiple chronic diseases. This paper aims to provide a review of the impact of caring for individuals with multimorbidity.

The literature review covers two research objectives:

1. To generate themes based on the study objective. By familiarising with data, the researcher will identify meaning across the data set related to providing answers to the research questions.
2. To identify the existing gap in the literature, which will inform the researcher on the type of questions that need to be addressed and the type of study needed to address the question for future research agendas.

In achieving the above objectives, the researcher puts into consideration the possibility of searching broad literature sources from a range of relevant databases, which will help to map out key concepts that underpin the experience of family caregivers of older adults with chronic illness. This approach is meant for the researcher to provide an overview of the available research evidence. Hence, the choice of a Scoping Review.

## **Method**

A scoping review methodology as described by Arksey and O'Malley <sup>6</sup> and further recommended by Levac et al <sup>7</sup> was selected for this study to help identify research gaps and synthesise current literature relevant to the research questions. Scoping Review is one of the newer reviewing types, that aims to map key concepts that underpin a research area. A Scoping Reviews also provides a broader view of the topic while still performing a systematic search<sup>8</sup>, which allows for a wider search of literature sources with many different designs. As described by Arksey and O'Malley, a Scoping Review process involves five different stages: (1) identification of the research question; (2) identification of relevant studies; (3) study selection; (4) charting the data; and (5) collating, summarizing, and reporting results. For quality

improvement, this Scoping Review of the literature was conducted using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) <sup>9</sup>. The optional ‘consultation exercise’ recommended by Arskey and O’Malley was not conducted <sup>6</sup>. No formal review protocol was published for this scoping review. The **identification of research question** sought to answer the question: what are the lived experiences of family caregivers of older adults with chronic disease?

### **Identification of relevant studies**

A detailed summary of the literature search is provided in Fig. 1. First, to get an overview of the relevant literature, free text terms such as ‘‘family caregivers’’ ‘‘elderly’’ ‘‘support intervention’’ and ‘‘population ageing’’ were purposefully searched on Google Scholar. Later a search strategy was developed for the identification of relevant studies. A Scoping Literature Review was conducted between 15<sup>th</sup> October 2020 to 30<sup>th</sup> September 2021 using relevant electronic databases: Academic Search Elite, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medical Literature Analysis and Retrieval System Online (MEDLINE), SCOPUS, PubMed, ISI web of science/knowledge and Science Direct, using a combination of the following keywords in MeSH terms. Individual searches were combined using ‘‘OR’’ Boolean operator as a single group. Each single group was then combined using the ‘‘AND’’ function to produce a list of citation. keywords used in this search strategy were associated with ‘‘family’’, ‘‘caregivers’’, ‘‘older adults’’, ‘‘caregiver burden’’, ‘‘support’’, and ‘‘chronic diseases’’ A research librarian assisted in performing the article searches.

### **Inclusion criteria**

The Population, Concept, and Context framework <sup>6</sup> was employed to determine which articles were eligible for inclusion in the review. **Population:** Family caregivers of older adult with chronic disease. **Concept:** Concepts related to family caregivers’ participation in care of older adults with chronic disease. **Context:** family caregivers caring for older adults at home; Type

of evidence: descriptive, qualitative, and quantitative methodologies, review, peer-reviewed studies written and published in English, published between July 2011 and July 2021.

### **Exclusion criteria**

In screening the material, articles that failed to meet the objectives of this review were excluded, such as those that did not focus on family caregiving nor older adults with chronic disease. Studies were excluded if they: (1) involved family caregivers who were less than 18 years old; (2) articles that did not provide a comprehensive understanding of the experience of family caregivers of older adults with chronic illness but instead focused more broadly on family caregiving; (3) reported outcomes of patients and no focus on family caregivers.

### **Study selection**

This third stage of Arksey and O'Malley's model involves reviewing and selecting articles. The researcher screened titles and abstracts. Full-text articles included were reviewed independently by two reviewers. Before reaching a consensus, the author independently appraised the quality of the articles. This review stage collaborated with two independent members from the College of Nursing, Midwifery and Healthcare at the University of West London, UK. Consensus on differences regarding articles to be included or excluded was reached. Eligible studies identified were included for the review. Due to inaccuracy of keyword and index-based search queries the researcher manually searched and extracted retrieved but excluded articles. Reference management software RefWorks (Cite Them Right - Harvard) was used to organise and store the literature and all duplicates removed.

### **Data extraction and analysis**

Data were extracted and **charted** for review. Chart information included author(s), year of publication, country, research design, aim of the study, sample size and study setting, key

findings, value and contribution, limitations (see Table 2). This chart was used to identify similar categories or themes to describe outcomes and results.

### **Collating, summarising, and reporting the data**

In this last stage of Arksey and O'Malley's framework the authors followed the advice of Levac et al.<sup>7</sup> to develop a descriptive summary of the collated results. The literature was organized according to the burden, coping, support and support delivery system of family caregivers of older adult with chronic disease. In the end, four qualitative, five quantitative, and two mixed studies were included in this review (n=11). Some studies included data related to more than one category. Description of Studies: of the 11 studies, 4 (36%) adopted a descriptive design; 3 (27%) were reviews; 1(10%) adopted an interpretative design and 3(27%) were cross sectional studies. The included studies were conducted in the following countries: Nigeria (n = 4), USA (n = 3), Canada (n = 2), China (n=1), United Kingdom (n=1)

### **Quality assessment**

The researcher then conducted a quality appraisal to assess the quality of included literature. The Critical Appraisal Skills Programme Qualitative Checklist (CASP, 2018) (see Table 1.) tool was used to appraise the quality of studies included in the scoping review. This ten-question qualitative checklist is widely used in health and social care research. Researchers consider it due to its clarity and ease of use. The tool allows for the appraisal of both qualitative and quantitative data<sup>10</sup>. All eleven studies are assessed for methodological quality assessment. The methodological quality of studies varied. All eleven studies met the four screening criteria of 'Statement of Research Aims', 'Methodology Appropriate', 'Clear statement of findings' and 'Value of research'. However, only six studies showed 'clear ethical approval' and 'recruitment strategy'. Also, seven studies showed 'rigour in data analysis', 'appropriate research design' and 'data collection'. Five of the studies emerged as high-quality papers, two as moderate quality papers and four as low-quality papers.



**Table 1. Critical Appraisal Skills Programme Qualitative Checklist (CASP,2018)**

| Author and year                  | Q1<br>Statement<br>of research<br>aims? | Q2<br>Methodology<br>appropriate? | Q3<br>Research<br>design<br>appropriate? | Q4<br>Recruitment<br>strategy<br>appropriate? | Q5<br>Data<br>collection<br>appropriate? | Q6<br>Researcher/<br>participant<br>relationship? | Q7<br>Consideration<br>of ethical<br>issues | Q8<br>Data<br>analysis<br>rigour? | Q9<br>Statement<br>of<br>findings? | Q10<br>Value of<br>research | Scoring |
|----------------------------------|-----------------------------------------|-----------------------------------|------------------------------------------|-----------------------------------------------|------------------------------------------|---------------------------------------------------|---------------------------------------------|-----------------------------------|------------------------------------|-----------------------------|---------|
| (Faronbi, 2018)                  | Y                                       | Y                                 | Y                                        | Y                                             | Y                                        | CT                                                | Y                                           | Y                                 | Y                                  | Y                           | 9.5     |
| (Faronbi <i>et al.</i> , 2019)   | Y                                       | Y                                 | Y                                        | Y                                             | Y                                        | CT                                                | Y                                           | Y                                 | Y                                  | Y                           | 9.5     |
| (Oyegbile and Brysiewicz, 2017)  | Y                                       | Y                                 | Y                                        | CT                                            | Y                                        | CT                                                | Y                                           | Y                                 | Y                                  | Y                           | 9       |
| (Ploeg <i>et al.</i> , 2020)     | Y                                       | Y                                 | Y                                        | Y                                             | Y                                        | CT                                                | Y                                           | Y                                 | Y                                  | Y                           | 9.5     |
| (Cho and Kim, 2016)              | Y                                       | Y                                 | Y                                        | CT                                            | Y                                        | CT                                                | CT                                          | Y                                 | Y                                  | Y                           | 8.5     |
| (Hendrix <i>et al.</i> , 2011)   | Y                                       | Y                                 | Y                                        | Y                                             | Y                                        | N                                                 | N                                           | Y                                 | Y                                  | Y                           | 8       |
| (Lambert <i>et al.</i> , 2017)   | Y                                       | Y                                 | CT                                       | N                                             | N                                        | CT                                                | Y                                           | CT                                | Y                                  | Y                           | 6.5     |
| (Parkinson <i>et al.</i> , 2017) | Y                                       | Y                                 | Y                                        | N                                             | N                                        | N                                                 | N                                           | CT                                | Y                                  | Y                           | 6       |
| (Hu, 2019)                       | Y                                       | Y                                 | Y                                        | N                                             | N                                        | N                                                 | N                                           | CT                                | Y                                  | Y                           | 6       |
| (Michael <i>et al.</i> , 2016)   | Y                                       | Y                                 | Y                                        | Y                                             | Y                                        | CT                                                | CT                                          | Y                                 | Y                                  | Y                           | 9       |
| (Sullivan and Miller, 2015)      | Y                                       | Y                                 | CT                                       | N                                             | N                                        | CT                                                | CT                                          | CT                                | Y                                  | Y                           | 6       |
| Total                            | 11                                      | 11                                | 9                                        | 5                                             | 7                                        | 4                                                 | 5                                           | 7                                 | 11                                 | 11                          |         |

Y = Yes: 1point

CT= can't tell 0.5 points

N=No 0 points

Scoring system:

High-quality paper: Scores 9–10

Moderate-quality paper: Scores 7.5-9

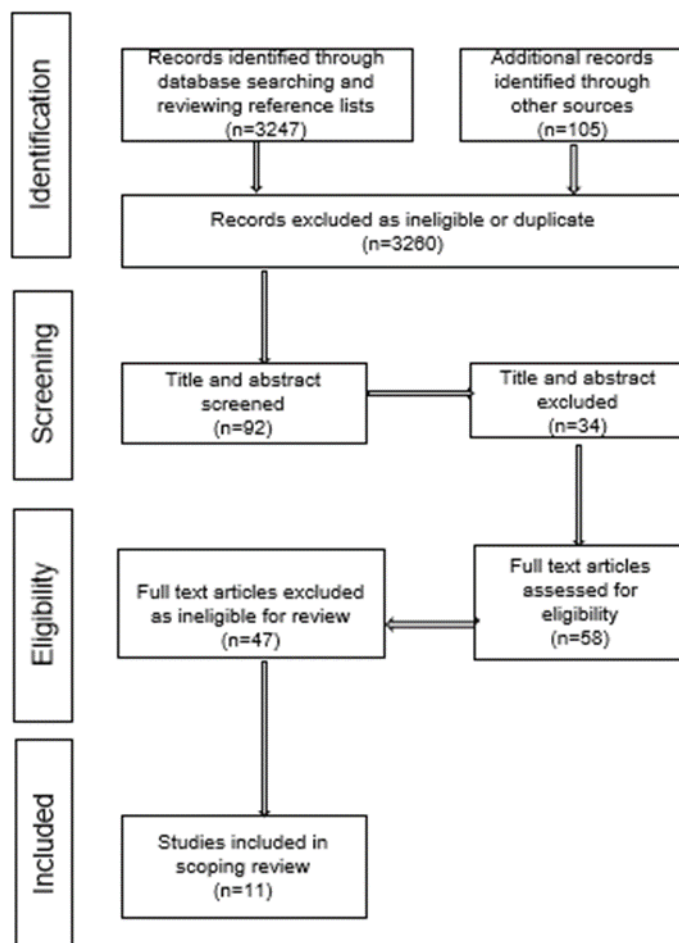
Low-quality paper: Less than 7.5

Exclude: Less than 6

## Results

3352 records were identified. Duplicates and ineligible records were excluded. Results were narrowed to 92 peer-reviewed articles, titles and abstracts of the studies were reviewed, and 58 full-text articles were assessed for eligibility. After reviewing the complete text, 30 articles were excluded, with 11 articles included in the literature review (see Figure 1). A final search of databases was conducted to be sure that all relevant literature was captured. The literature review was considered complete when the same articles began to appear repeatedly in the electronic searches. Included studies are listed in Table 2. All document types were searched with a focus on primary research studies.

**Fig. 1. PRISMA flow diagram of Scoping Review process.**



## Themes

After data extraction, the literature was discussed and synthesised into a descriptive summary of the data extracted. Due to the wide variability of studies concerning the study design, population, types of intervention and outcomes, we decided that a Narrative Synthesis constitutes the best tool to synthesise the findings of the different studies included in the review. Firstly, a preliminary synthesis was undertaken to describe each of the included studies: summarising the same features (study design and setting, intervention, outcome, the value of contribution and limitation for each study and in the same order, listing and presenting results in a tabular format. Then the results were discussed and structured into themes as follows.

### Theme 1: Burden and coping

This theme was identified in existing literature <sup>3,11,12</sup>. They explained that caregivers of older adults with chronic illnesses are exposed to the burden associated with their caregiving activities. As a result, caregivers are exposed to many stressors while carrying out their caregiving activities. The umbrella phrase for the problems experienced by caregivers is termed "caregiver burden", an all-encompassing term used to describe the physical, psychological, and financial toll of providing care <sup>11,13</sup>. Many caregivers experience demand on their time and resources <sup>14</sup>, health deterioration <sup>15</sup>, a new world - understanding medical information/jargon <sup>3</sup>, mental and physical exhaustion <sup>4</sup>. However, the development of the concept of burden for use in research lacks consistent conceptualisation and operational definitions. Critical attributes of burden include subjective perceptions, multidimensional phenomena, dynamic changes, and overload. Therefore, it is essential to identify the different sources of burden and provide directions for caregiver intervention <sup>11</sup>.

Although a growing body of knowledge on the burden of family caregivers, coping with this burden could vary <sup>11</sup>. Faronbi, (2020) reported that the coping mechanism might not be yielding the desired result. It, therefore, calls for urgent attention to promote effective coping among caregivers. He argues that a significant proportion of family caregivers engage in unhealthy coping strategies that are rather harmful. For example, strategies such as substance abuse, self-distraction and denial may confer temporary relief for the burden <sup>16</sup>. Despite the burden associated with caregiving, caregivers look beyond the burden of caregiving, making them want to persist in the caring process, seeing caring for their relatives as an investment <sup>12</sup>. Caregivers' commitment to preserving life makes them aid their family members to the detriment of their own well-being. Hence, it is vital to address the needs of family caregivers to help them cope with the burden of caregiving. To provide support to chronically ill older adults <sup>17</sup>.

Existing literature reveals studies on specific chronic diseases in older adults, as most interventions for managing chronic disease focus on a single condition. Literature reveals several articles on single chronic conditions, cancer <sup>18</sup>, stroke <sup>19</sup>, Alzheimer <sup>20</sup>. This undermines the overall effect of caregiver's burden on caring for the elderly with multiple chronic diseases <sup>12</sup>. Conceptual clarity on caregivers' experience of multiple chronic conditions amongst older adults is lacking. Little is known about the challenges or coping mechanisms when caring for the elderly with multiple conditions. Hence, the need to explore their caregiving experiences for overall well-being and quality of life. This Scoping Review will start by attempting the first research question: ***What are the challenges and coping mechanisms associated with informal caregiving of the elderly with chronic illness?***

## **Theme 2. Support and intervention**

Family caregivers provide a significant amount of caregiving hours and intense caregiving tasks. A qualitative design guided by a phenomenological approach studied caregivers' lived

experiences, concluding that caregivers' performance could run contrary to their well-being<sup>12</sup>. Despite their invaluable contributions, it is reported that family caregivers often operate in a reality of inadequate social support. As such, Family caregivers are at heightened risk for poorer physical and mental health than their non-caregiving counterparts<sup>21</sup>. Hence the need to promote caregivers' support and well-being.

There is increasing attention in research as well as government policy on support to family carers. However, supporting family carers may prove to be a more complex endeavour than one initially might be led to 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'<sup>22</sup>. Notably, there is a growing body of literature discussing various support strategies for family caregivers. For example, in their Descriptive Study, Cho and Kim (2016) in the Georgia United States reveal evidence-based interventions implemented through programs that complement the National Family Caregiver Support Program (NFCSP). The United States of America and the United Kingdom are some of the few countries that support family caregivers exclusively by law<sup>23</sup>. Such deliberate efforts by the government could increase family caregivers support awareness.

Some other approaches include psycho-educational programmes, focused on preparing primary family caregivers for the role of supporting a relative with advanced cancer at home<sup>24</sup>, providing relevant informational support to caregivers<sup>12</sup>, referring caregivers to additional resources<sup>25</sup>. Other successful interventions by researchers include person-centred interventions for supporting family carers via the component of facilitation<sup>26</sup>, Individualised Caregiver training<sup>27</sup>. Some researchers<sup>28</sup> base their conclusion on specific training in specific areas of various illnesses. While others<sup>29</sup> centre on family caregivers networking in groups with peers, either for social or learning needs purposes, resilience building and investment.

In contrast, a meta-review of the international evidence on family caregiver support interventions found no evidence of improvements to family caregiver stress, burden, psychological well-being, or quality of life based on the above-listed support measures. There is a diversity of information about how best family caregivers of an older person should be supported, leading to various interpretations of how support is measured and operationalised. The following question then arises: *How can caregivers be supported best?*

### **Theme 3: Support delivery system**

The need to support family caregivers cannot be overemphasised. It spans from caregivers need for sustainable support <sup>30</sup>. Caregiver's experience could inform interventions and raise awareness about the importance of providing support and resources at multi-levels <sup>31</sup>. Some studies make projections on demand for informal care among older people. These studies discuss possible policy measures to alleviate the mounting pressure on the demand for informal care <sup>32</sup>. Therefore, it is vital to understand the needs of family caregivers and how they may impact the delivery of support interventions and assist in developing a model of care for family caregivers <sup>33</sup>.

The suggestion of family caregivers support policy at all levels paves a way to investigate further the perception of policy implementors on support for family caregiving. For interventions to be successful, attention should be given to how policy implementors interact and engage with caregivers. Supportive and unsupportive interactions are shown to impact caregivers' perceptions, decision making and coping <sup>30</sup>.

A partnership approach to supporting needs assessment with family caregivers of older persons suffering from chronic illness is recommended to work well with family caregivers. 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 the support services, see them as valuable and view the intervention related to their perception of need <sup>34</sup>. Furthermore,

caregivers must trust the people providing services, see them as valuable and view the intervention related to their perception of need <sup>34</sup>. The family caregiver support system cannot be undertaken by one entity alone. It is a product of collaborative efforts by different parties with their history and expertise <sup>23</sup>. A care model allows several practitioners to interact with the caregiver to assess and determine the optional interventions.

An underlying problem beneath this absence of family caregiver support programmes lies in the lack of general awareness of caregiving <sup>35</sup>. A related question is how to legitimise family carer support effectively. Hence, where pertinent, consideration should be given to the potential merits of officially recognising family carers as ‘care recipients’; therefore, they are formally acknowledged as ‘worthy’ within the healthcare system <sup>36,37</sup>. The formal recognition of family caregivers may help justify much-needed resources and allow healthcare workers to allocate time and, where appropriate, offer interventions. Also, continuous demand for caregivers' support means that caregivers need, and perspectives need to be integrated into future service planning and decision-making processes in partnership with statutory and voluntary bodies.

*The concept of support gives rise to the final research question; **What is the perception of those implementing policy in terms of family caregiving?***

**Table2: Review literature**

| <b>Author year<br/>title country</b>                                                                                                                         | <b>Study design</b>                                                                                                                                                                         | <b>Sample<br/>size and<br/>sites</b>                                                                                                                 | <b>Key<br/>findings</b>                                                                                                                                            | <b>Value and<br/>contribution</b>                                                                                             | <b>Limitations</b>                                                                                                                                                                                    |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Faronbi<br>2018<br>Correlate of<br>burden and<br>coping ability<br>of caregivers<br>of older<br>adults with<br>chronic<br>illness in<br>Nigeria."<br>Nigeria | A quantitative<br>cross-sectional<br>study to assess<br>the burden and<br>coping<br>experience of<br>caregivers of<br>older adults with<br>chronic illness.<br><br>Ethical<br>consideration | Data were<br>collected<br>among<br>325<br>caregiver<br>s of older<br>adults<br>living<br>with<br>chronic<br>illness in<br>Osun<br>State,<br>Nigeria. | Over 59% of<br>caregivers<br>experienced<br>severe<br>burden,<br>associated<br>with religion.<br>Coping<br>strategies<br>used include<br>religion and<br>planning. | Healthcare<br>providers<br>should<br>consider<br>intervention<br>s to promote<br>the use of<br>effective<br>coping<br>skills. | The<br>assessment<br>of burden<br>and coping<br>abilities at<br>one single<br>point in<br>time, might<br>have made<br>studying<br>patterns and<br>variations of<br>coping<br>strategies<br>difficult. |



|                                                                                                                                                               |                                                                                                                                                                        |                                                                                                                         |                                                                                                                             |                                                                                                                  |                                                                                                                                                       |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                                                                                                                                               |                                                                                                                                                                        |                                                                                                                         |                                                                                                                             |                                                                                                                  |                                                                                                                                                       |
| Faronbi et al. 2019<br>Caring for the seniors with chronic illness: The lived experience of caregivers of older adults''<br>Nigeria                           | A qualitative design guided by an interpretive phenomenology. To describe the lived experience of caregivers of older adults in Nigeria.<br>Ethical approval           | Fifteen caregiver s of older adults with chronic illness were interviewed, from different parts of Osun State, Nigeria. | This study provides insight into the burden of care of older adults with chronic illness. Caregivers'                       | Intervention programme should be designed to support the caregivers thereby improving their well-being.          | Exclusion of participants that were unable to visit site might have implication on the generalisati on of the finding.                                |
| Oyegbile and Brysiewicz 2017<br>Exploring caregiver burden experienced by family caregivers of patients with End-Stage Renal Disease in Nigeria''<br>Nigeria. | A complementary mixed method data collection strategy. To explore the caregiver burden of family caregivers of End-Stage Renal Disease (ESRD)<br>Ethical consideration | The three research settings consisted of two state hospitals and one private hospital, West Nigeria.                    | Result indicated that family caregivers experienced moderate to severe burden, which is high compared to the other studies. | Understandi ng the extent of caregiver burden, allows appropriate strategies and intervention s to be developed. | The limited sample size of this study, and the fact that the study was only conducted at three sites does not permit generalisati on of the findings. |

|                                                                                                                                                                                                       |                                                                                                                                                                                                                                                  |                                                                                                                                                                                        |                                                                                                                                                                                                                          |                                                                                                                                                                                                                                          |                                                                                                                                                                                                                                   |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Ploeg et al.<br>2020<br>Caregivers of<br>older adults<br>with<br>dementia and<br>multiple<br>chronic<br>conditions:<br>Exploring<br>their<br>experiences<br>with<br>significant<br>changes<br>Canada. | A mixed method<br>randomised<br>controlled trial<br>and qualitative<br>descriptive study.<br>Aim: to explore<br>Significant<br>changes<br>experienced by<br>caregivers and<br>how caregivers<br>coped with these<br>changes.<br>Ethical approval | 199<br>caregiver<br>s<br>participat<br>ed in the<br>larger<br>trial; 72<br>caregiver<br>s<br>interview<br>ed for the<br>qualitativ<br>e strand<br>of the<br>mixed<br>methods<br>study. | Study results<br>indicate<br>caregivers of<br>older adults<br>with multiple<br>chronic<br>conditions<br>experienced<br>many<br>changes in<br>their<br>caregiving<br>journey<br>resulting in<br>increasing<br>complexity. | Health care<br>providers<br>should<br>consider<br>both the<br>caregiver<br>and care<br>recipient as<br>clients in the<br>circle of<br>care and<br>facilitate<br>their linkage<br>with health<br>and<br>community<br>support<br>services. | The sample<br>of<br>participants<br>included<br>only a small<br>proportion<br>of those<br>living with<br>inadequate<br>financial<br>means.<br>Recruitment<br>was through<br>one body.<br>There could<br>be bias in<br>the result. |
| Cho and Kim<br>2016<br>A Study on<br>Family<br>Caregiver<br>Support<br>Programs in<br>the<br>U.S.A.: The<br>Case of the<br>State of<br>Georgia''<br>United States<br>of America                       | A qualitative<br>evaluation/descri<br>ptive study.<br>Aim: Introduces<br>programmes that<br>support family<br>caregivers<br>looking after<br>older adults.                                                                                       | U.S.<br>federal<br>and state<br>govt.<br>plans and<br>reports<br>on family<br>caregiver<br>support.<br>Korean<br>govt.<br>plans and<br>reports on<br>family                            | Findings<br>show that<br>one-on-one<br>evidence-<br>based<br>programmes<br>(E.B.P.s) for<br>family<br>caregivers<br>are both<br>economical<br>and effective<br>in assisting<br>caregivers.                               | The<br>implementat<br>ion of<br>E.B.P.s<br>funded by<br>the<br>government<br>is a useful<br>reference for<br>rapidly<br>aging<br>countries.<br>For<br>caregiver<br>support, can                                                          | Restrictions<br>in the<br>availability<br>of public<br>documents,<br>the research<br>consists of<br>an<br>exploratory,<br>descriptive<br>study rather<br>than in-<br>depth<br>case-study.                                         |

| evidence-based programs U.S.A.                                                                                                                 |                                                                                                                                                               | caregiver support.                                                                                                            |                                                                                                                                                                         | effectively prevent a crisis in caregiving.                                                                          |                                                                                               |
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| Hendrix et al. 2011<br>“Individualised Training for Caregivers of Hospitalised Older Veterans”<br>United States of America.                    | A qualitative pilot study. To examine the feasibility of delivering an individualised caregiver training program before hospital discharge of older veterans. | 50 caregiver patient dyads. Study conducted in four medical surgical units at the V.A. Medical Centre, Durham, North Carolina | Providing an individualised training program to informal caregivers of hospitalised older veterans associated with increased self-efficacy and caregiving preparedness. | This study has the potential to assist caregivers in their home after hospital discharge.                            | Refusals to participate, lack of flexibility and appropriate timing for participants consent. |
| Lambert et al. 2017<br>“Impact of informal caregiving on older adults’ physical and mental health in low-income and middle-income countries: a | A quantitative secondary cross-sectional analysis study. To determine the level of burden experienced by caregivers.<br><br>Ethical approval                  | Caregivers in Ghana (n=143), India (n=490) and Russia (n=270)                                                                 | Caregivers mostly cared for one person and provided financial, social/emotional and/or physical support, but received little support                                    | Policy and programme initiatives are needed to ensure that caregivers in low- and middle-income countries can fulfil | length and time might have affected quality of responses to the caregiving-related questions. |

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| cross-sectional, secondary analysis’’<br>Canada.                                                                                                               |                                                                                                                                |                                                                                        | themselves.<br>Caregivers reported lower Q.O.L.                                                  | their role without compromising their own health.                                                                                     |                                                                                                                |
| Parkinson et al., 2017<br>‘‘Investigating what works to support family carers of people with dementia: a rapid realist review’’<br>United Kingdom.             | Rapid Realist Review: investigates ‘what works to support family carers of people with dementia.                               | Secondary data.                                                                        | Resilience-building’ is central to ‘what works to support family carers of people with dementia. | The resulting model and Programme Theories respond to the burgeoning need for a coherent approach to carer support.                   | The model does not represent an exhaustive taxonomy. Subject to further refinement during subsequent ‘testing’ |
| Hu 2019<br>‘‘Projecting future demand for informal care among older people in China: the road towards a sustainable long-term care system’’<br>United Kingdom. | A quantitative review. To discuss possible policy measures to alleviate the mounting pressure on the demand for informal care. | A total of 17,708 individuals in 28 provinces across China participated in the survey. | The study projects that the demand for informal care will increase.                              | Special attention should be paid to informal carers to whom older people have access. continued policy reforms and innovations needed | Study done in single area, does not permit generalisation.                                                     |

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|                                                                                                                                                                               |                                                                                                                                                  |                                                                                        |                                                                                                                                     | towards a sustainable long-term care system.                                                                                                                                           |                                                                                                                   |
| Sullivan and Miller, 2015<br>Who is taking care of the caregiver?’’<br>United States<br>keywords: caregiver, multidisciplinary team communication, loved one, chronic disease | Qualitative: article review. To review common caregiver challenges and determine how providers can address and help caregivers more effectively. | N/A                                                                                    | This article has raised awareness that living with a chronic illness is truly a family affair.                                      | Therefore, family caregivers must be seen as members of the health care team and do their best to ensure they receive the same mental and physical health care and access to wellness. | N/A                                                                                                               |
| Michael et al., 2016<br>‘‘Public Awareness and perception on Care for the Elderly among Funtua Residents in Kastina State,                                                    | A quantitative cross-sectional descriptive survey design. To evaluate public awareness and perception towards care for older adults.             | 150 participants were recruited for the study using purposive and convenience sampling | The result shows that most of the participants (90%) have relatively good knowledge of the primary care of the elderly, with a high | Significant efforts are required in health to educate the public about the activities of daily living and ways of caring for older adults                                              | The narrow scope of this study limits the generalisability of the findings to all areas in the study environment. |

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| North-West<br>Nigeria’’<br>Nigeria. |  | technique<br>s. | positive<br>attitudinal<br>predispositio<br>n. | with chronic<br>illness. |  |
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## Discussion

This Scoping Review provides an overview of the experiences of family caregivers for older adults with chronic illness. The research findings reveal that family caregivers experience physical, psychological, and financial burdens when caring for the elderly with single conditions. However, a lack of conceptual clarity about multiple conditions exists within the reviewed literature. In providing informal care, family caregivers in developed and developing societies encounter various difficulties due to their caregiving roles. Consequently, they may require different forms of support to sustain this overwhelming role. The need to promote caregivers' support and well-being is deemed necessary, especially with a looming ageing population, inadequate support to caregivers and prevalent chronic conditions amongst the elderly <sup>38</sup>. The identification of appropriate family caregiver intervention is essential for future policy practice for few suggested reasons. Firstly, greater emphasis on providing support for family caregivers in developing societies will mitigate the burden of caregiving. Secondly, family caregivers and care recipients' quality of life will be positively affected. The review unveiled some diverse interventions that describe how best to engage and support family caregivers. Existing literature suggest support networks at multiple levels, interact and engage with family caregivers, to be better informed about decision making.

This paper is based on my PhD research to explore the lived experiences of family caregivers' burdens, coping mechanisms, and support delivery systems. Although there is a great deal of writing about and research into family caregivers experience of older adults with single chronic conditions, surprisingly, there is little detailed discussion on the experience of family

caregivers of older adults with multiple chronic conditions. Further research in this area could enable the researcher identify cases of family caregivers of older adults with multiple chronic illnesses. Moreover, why is it essential to research this phenomenon? Family caregivers are the backbone of the healthcare system. Over time, caregiving takes a tremendous toll on the caregiver. Therefore, support from family, friends and, most importantly, government assistance is required. The need to identify support requirements of family caregivers of this population and support network as a precursor to meeting their needs is suggested. Recognition of support needs for family caregivers of older adults with multiple chronic illness and a deeper understanding of how these needs can be met is deemed necessary to add to the study area's limited and existing knowledge base. This could develop tailored and sustainable support for this population.

Considering the importance of family caregiving, it is, surprising that it has attracted little scholarly attention globally. This could be explained by the fact that countries lack awareness and evidence on family caregivers' lived experiences. Understanding these themes also revealed a growing body of knowledge on the experiences of family caregivers in developed countries. However, few studies exist in developing nations. Developed countries should be a concrete reference point for other countries experiencing a rise in older persons. Thus, critical implications for policy and practice that inform an agenda to improve family carer support. With an emphasis on the enactment and implementation of family caregivers support policy at all levels (local, state, and federal).

### **Limitation**

It could be suggested that the aims and study design of reviewed studies were somewhat disparate. They were ranging from assessing experience to exploring caregiver burden or programmes that support caregiving. Nevertheless, all selected studies referred to the burden,

coping mechanism, and support needs of the elderly with chronic illness. Findings might have been different if studies had focussed on a range of qualitative studies.

### **Way forward**

Future research could focus on more information needed in this area to inform policy implementors and support networks. The potential merits of officially recognising family carers 'worthy' within the healthcare system should be given consideration. This article informs on the need to further research in this area, take for example in areas where qualitative research is lacking. This research could inform policy practice and contribute to the improvement of the informal care system.

### **Conclusion**

Our findings suggest that awareness for the support of family caregivers can be better promoted when family caregiving can be lauded as a virtuous act that aids in reducing the care deficit in societies. By 2030, the number of people aged 60 and above will be more than doubled. As society reaches this important demographic turning point, more people will have to take up the caregiving role. It only makes sense that caring becomes intuitive and a shared aspect of all cultures at all levels of leadership. This scoping review lays the groundwork for future research on the experiences of family caregivers of older adults with multi chronic illnesses. Also, for culturally sensitive interventions to be designed such that appreciation for caregivers is enhanced even as their burden is reduced. Specifically, the framework of burden, coping and support delivery system can be used to analyse qualitative data, which would generate new insights into the experiences of family caregivers around multiple chronic illnesses.

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