Working Together to Support Family Caregivers of Older Nigerian Adults with Chronic Illness at Home

Jika, Barbara Member, Khan, Hafiz T.A. ORCID logoORCID: https://orcid.org/0000-0002-1817-3730 and Lawal, Muili ORCID logoORCID: https://orcid.org/0000-0002-1502-3884 (2023) Working Together to Support Family Caregivers of Older Nigerian Adults with Chronic Illness at Home. Journal of Population Ageing. ISSN 1874-7884

http://dx.doi.org/10.1007/s12062-023-09436-3

This is the Accepted Version of the final output.

UWL repository link: https://repository.uwl.ac.uk/id/eprint/12118/

Abstract

In Nigeria, the burden of caring for older adults with chronic illness at home has a significant impact on family members that are the primary caregivers. This calls for support from relevant stakeholders that can help improve caregiver outcomes. Despite having in place an informal social support network that comprises of family, friends, religious and community groups, it is not enough to relieve the burdens of care. Studies suggest collaborative efforts between relevant stakeholders to support family caregivers. This study therefore aims to explore the perception of policy implementers, healthcare professionals, community, and religious leaders on support for family caregivers of cohabiting older adults with chronic illness in Benue, Middle-belt Nigeria. A convenient purposive sampling technique guided the recruitment process and in-depth semi-structured interviews was used to collect data from fourteen respondents in this qualitative study. Findings revealed that family caregivers needed three types of support: (1) create public awareness to recognise the family caregivers' role; (2) identification of family caregivers'; (3) enhance access to training services that will help improve home care support. As a result: (1) health and wellbeing of family caregivers' will be promoted; (2) a data base of family caregivers' will be generated; (3) an organised system will be in place for stakeholders to assist. Therefore, relevant stakeholders such as community leaders, religious leaders, Healthcare professionals and non-governmental organisations with government taking the lead should work towards creating a programme, committee or department that addresses family caregivers' immediate needs. This requires each stakeholder playing a specific vital role that focuses on an important holistic change to support family caregivers'

Key words: Nigeria; Chronic illness; Family caregivers' support; support network; older adults.

Introduction

Several African countries rely heavily on informal care provision for long-term care (Hu, 2019). Providing care for a sick family member is a normative role embedded within African culture (Asuquo et al., 2013). The Nigerian informal care system is based on an assumption that, family members should care for their loved ones. Such as older adults suffering from chronic illnesses, who are unable to maintain their independence to manage basic physical needs (Akanji et al., 2002; Asuquo et al., 2013; Okediji et al., 2017). This could be due to cultural expectations and family relationships with care recipients (Faronbi, et al., 2019). Informal care predominates in developing countries such as Nigeria and other African countries in the Sub-Saharan region, which are collectivist in orientation (Kaschowitz & Brandt, 2017). Apparently, informal caregiving systems are simultaneously dwindling due to socio-demographic factors within families experiencing infertility, higher migration, less intergenerational co-habitation, divorce and re-marriage (Victor, 2008). As a result, the burden of long-term care increasingly falls on the available family caregivers. This is a significant contribution by family caregivers who form the backbone of health care system globally (Fernandes & Angelo, 2016; Goldberg & Rickler, 2011). However, their role appears hidden and unrecognized (Reinhard et al., 2014). Following our research on the lived experience of family caregivers of older adults with chronic illness in Benue state, Nigeria, we found that they face challenges caring and finding support, which is gotten majorly from family and friends. In this paper we focus on the role and recommendations of other relevant stakeholders. We sought to understand the perspective of policy implementers, healthcare professionals, religious and community leaders on support for family caregivers.

Diverse care burdens and health effects among caregivers

The need to care for older adults with chronic illness is left in the hands of few family members and friends, who are without appropriate skills and training to take up the caregiving role and to meet the health need of their family members (Reinhard et al., 2014; Reinhard et al., 2019). In caring for older adults family caregivers execute complex task like those carried out by trained healthcare professionals (Levine et al., 2003; Reinhard et al., 2014; Reinhard et al., 2019). However, as much as family caregivers feel needed, they are also overwhelmed, and burdened with care (Faronbi, Joel Olayiwola et al., 2019). Literature reveals experiences of diverse burdens and health effects among family caregivers. This includes declined physical health as well as psychological and financial burden'' (Ojifinni & Uchendu, 2022). Previous research studies (Son et al., 2007; Zarit & Zarit, 2015) report 'caregiver burden' to be when one suffers mentally, physically and financially whilst caring for another. Consequently, the elevated burden can have a negative effect on the health of carers (Agrawal, 2013; Ojifinni & Uchendu, 2022). Such effects could result to loneliness, depression, anxiety, heart diseases and other psychological problems (Adebusoye et al., 2011; Adewuya & Oladipo, 2020; Faronbi, et al., 2020; Ojagbemi et al., 2016). Caregivers are stressed by the demands of caregiving; some caregivers experience social isolation (Faronbi, et al, 2019; Lee et al., 2022), and are not able to attend functions or make out time for other activities, this can have detrimental effect on family members caring for older adults (Faronbi, et al., 2019; Lee et al., 2022).

Support for family caregivers

Social support is regarded as the active involvement and engagement of a social network in the caregiver's ability to cope with stress while caring (Nolan, 2001). The social network could comprise of family members or friends, community groups, and other relevant stakeholders that may be required to help from time to time (Sit et al., 2004; Stoltz et al., 2004). Continuous and long-term care of older adults with chronic illness, in the absence of any form of support can be detrimental to the wellbeing of carers (Lim & Zebrack, 2004). Therefore, caring for older adults with chronic illness requires the support of family caregivers. Akanji, Ogunniyi and Baiyewu (2002) highlight that most caregivers in Nigeria preferred to care for older adults at home. This is due to several reasons, among these is 'available and adequate family support' (Akanji et al., 2002). This finding agrees with existing literature (Kogan et al., 2016; Noreen et al., 2021) that care for older adults is better at home where immediate family members, and friends will be easily available for immediate and adequate support. Some of the support documented in literature include a combination of emotional and practical support from people around them (Adedeji et al., 2022). Sometimes carers need someone for advice or to listen to their accounts of struggle and to empathize with their emotions during visits. Also, knowledge sharing regarding medical conditions of their loved ones is another form of support (Sit et al., 2004). There is a gap in the literature on how to support family caregivers of older adults with chronic illness at home in Nigeria. This paper presents findings from a qualitative study that explores the perception of Healthcare professional, community leaders, religious leaders and policy implementers in Benue, Nigeria on how best to support family caregivers of older adults with chronic illness. The following research questions guided the study; 1) how can family caregivers of older adults with chronic illness be supported best?

Methods

Study design and participants

An interpretive phenomenological approach was utilised because the study sought to understand the perception of policy implementers, healthcare professional, community, and religious leaders within the context of supporting family caregivers of older adults with chronic illness in Nigeria. All participants were recruited from Benue state, Nigeria.

Participant recruitment

Participants were recruited based on their leadership status, seniority, and influence. To gain access to the targeted population, key informants who had some knowledge regarding each support network were identified and contacted. Key informants linked the researcher to recruit Participants.

Sampling

Purposive sampling was utilised to recruit a support network from faith-based organizations, the community, hospitals, and government organizations. The in-depth interview samples were acquired using a convenience sampling technique. With the help of a research assistant, fourteen respondents who were willing to share their perceptions were recruited. The number comprised of three community leaders, three religious' leaders, three health professionals and five policy implementers. This is solely to obtain data from people of different social positions for a wider representation.

Data collection

The interviews were conducted in English language, participant for this stage were literate, could speak good English, and exposed to policy issues in Nigeria. Semi-structured interviews (see attached questionnaire table 2) with respondents were conducted in a relaxed, private, and conducive setting of their choice (Lopez 2004). Each interview was recorded for further analysis. Interview time for each participant varied, but a period of 30 to 45 minutes was allotted to enable participants narrate their experiences. The use of semi-structured interviews permitted the researcher to ask questions such as ''what is your perspective about family caregivers?'' ''How can you support family caregivers?''. Although these questions focused the interview, the researcher allowed each participant to narrate their experience as they chose with follow-up prompts such as: 'What do you think?' 'What can be done? 'Questions from the researcher.

Ethics

This study proposal was approved, and ethics clearance obtained by the University Research Ethics Committee in University of West London and Benue State University Teaching Hospital Nigeria. Participants consented to voluntarily participate in the study and were made aware to withdraw from the study at any time. Pseudonyms were used for privacy and confidentiality of participants. All recordings were safely kept in accordance to the data management and storage guidelines set out by the University of West London.

Data Analysis

To gain a general understanding of what the participants were saying, all fourteen audio-recorded interviews were listened to, then transcribed verbatim, for data analysis using Inductive Thematic Analysis by (Braun & Clake 2006). Transcripts were read severally to reflect on narrative descriptions. Coding information was applied using a data analysis software package called NVivo 12 (QSR International, 2018) to ascertain exhibited themes and patterns that could form similarities and differences or be connected to a particular concept or idea the researcher is investigating. Subsequently, codes with similar meanings were grouped together to create categories. In addition, themes were defined and named based on the relationship between categories. The themes were channelled to match the study objectives. Finally, descriptions of the phenomenon and concepts will be summarised into main findings.

Results

Participants' demographic characteristics

Table 1 shows the socio-demographic characteristics of the respondents. The respondents were comprised of health professional, policy implementers, community and religious leaders with age ranging from 42 years and 80 years old. Majority of the respondents were males 11 (78.5%) while 3 (21.4%) females. Some Respondents, 5 (35.7%) were in the age class of 51-60 years. this age bracket was closely followed 61 years and above comprising of 7 respondents. The highest formal educational qualification attained by most respondents was tertiary education with 7 (50%) respondents followed by 2 (14.2%) respondents with secondary education. Most respondents were Christians 13 (92.8%) and 1(7.2%) Muslim.

Themes

Theme 1: Identifying a support network

Through the interviews knowledge and perception of participants regarding supporting family caregivers, stems from the suggestion that both family caregivers and a support network need to be identified prior to any form of intervention. Identifying a support network entails having an understanding of the vital role that participants in the study can play in supporting family caregivers. The identified support network refers to individuals and groups that could help family caregivers achieve their goals as carers. Two sub-themes emerged from the first major theme: (a) identifying the need of the family caregiver; (b) The role of government and other stakeholders.

Identifying family caregivers and their needs

To identify a support network participants in the study talked about the need to also identify family caregivers. Through the interviews participants raised suggestions on how to go about identifying family caregivers and the role each support network can play in achieving the goal. The theme of 'identifying family caregivers and their needs' describes how family caregivers suffer in silence, and how family caregivers are situated in the background or context of caregiving, often as mere family members or objects and less frequently as agents with influence in patient care. Family caregivers are less likely to seek help and therefore suffer in silence. They prefer not to seek for support even though experiencing a difficult time as they struggle to meet basic needs, unless approached directly. Religious and community leaders describe the situation as suffering in silence, which culturally is regarded as virtuous act. However, participants reported the need to first 'identify family caregivers and their needs' to be able to support them.

> *''You know in our society in Tiv land people are not used to begging, they are too proud, so some of them even when they are suffering, they prefer to suffer in silence…''* (Ate, 62- years old).

> *''People are unaware of the struggles that caregivers are going through. They do not know where to identify them, and they do not know what they will need to be provided. Local government officials and ordinary people in the community that show concern and are active in the community can help to identify caregivers''* (Mal, 73-years old).

Family caregivers' needs were also identified to include financial assistance, provision of tangible items such as food, trainings to develop specific skills, positive attitude and knowledge about medical conditions. Due to diverse needs, the clergy also discussed the necessity of prioritising certain needs of family caregivers over others. One of the religious leaders describe how access to proper nutrition might be preferred over medical assistance.

> '*'There are diverse kinds of support that families who have an elderly, who has a chronic illness need.'' Support can be more than material; family caregivers also need Support around training.''*(Dosh, 55-years old)/

> *'' For some there may be a need for shelter, for others it may be a need for food or medical assistance. There are some cases where you may provide medical assistance, but these people cannot access proper nutrition at the end of the day, whatever medical assistance you give may not have the proper grounding in sound nutrition''* (Anon, 67-years old).

The role of government and the community

Another sub-theme identified was the role of government and the community in rendering support to family caregivers. Respondents shared their knowledge about how family caregivers rely so much on family and friends for support, because family and friends are easily accessible for support. However, support from family and friends is not enough source of support as explained by one of the community leaders. One of the religious leaders suggested it should be shared responsibility between the community and the government.

> *''All hands must be on deck. Family and friends supporting family caregivers alone is not enough. Both government, community (clan heads, community leaders), and others (foundations) have a role to play. The role of supporting family caregivers should be multi. "It is not the family's duty alone to care for the elderly. It is the duty of the community and society, and we depend on the government too much in this country. We can do things for ourselves."* (Isa, 65-years old).

Apart from community members, discussions with religious leaders revealed the role they can play in identifying family caregivers, when the issue of how family caregivers can be identified was raised

> *''As a church and as a pastor sometimes I visit my members in their homes to discover those that are suffering, I then jot their names down for the elders and the welfare unit*.''(Ate, 62-years old).

Suggestions were made by some of the respondents regarding government spearheading the process of supporting family caregivers, if they really want to. Mal a health care professional specifically suggested either the State Ministry of Health or the various Local Governments in the state. As part of establishing a formal support system he suggested a system whereby family caregivers are registered and there is a follow-up process to gather issues and for caregivers to know where to access help when needed.

> *'I think we should be able to provide something within either the State Ministry of Health and the federal Ministry of Health, particularly the state and local government ministry of health where carers can be registered as the primary caregiver, and for easy access to stakeholders for support''* (Mal, 73- years old).

Theme 2: Facilitators and barriers to provide and receive social support

All respondents acknowledged the role of caregivers to be extremely stressful with adverse effects on their health which requires some form of support from individuals, government, and other organizations to relieve the burden of care. The role of the government and other stakeholders (health professional, religious leaders, and community leaders) was highlighted by respondents to include fundraising, donations, counselling, and advice. All three religious leaders revealed that the church and the mosque should make deliberate efforts to have in place a policy to care and assist family caregivers. Anon suggested religious organisations to set aside a mandatory portion of finances for the sole purpose of supporting family caregivers of the elderly. Health care professionals suggested guidance and advice that could help.

> *''As a health professional, I can give guidance and advice to family caregivers of the elderly depending on what and what the patient needs are.''* (Ivy, 42-years old).

> *''As a church, we do raise funds to support those who are taking care of the elderly and are suffering from one thing or another in their homes.''* (Ate, 62-years old).

Channelling resources appropriately

All respondents expressed how channelling resources to family caregivers could be a challenge, despite the willingness by a social support network to want to support. It was evident that this sub-theme was a major challenge and could be a hindrance to relevant stakeholders that may want to support. However, some religious leaders and healthcare professional made suggestions as to how misappropriation of resources can be addressed.

> *"People want to support, but they want to be sure that the channel of support is genuine, and that these channels will reach the caregiver. A lot of people may collect this support and never get it to the appropriate persons.''* (Isa, 65-years old).

> *''The council of elders channel the money through the Deacons to such people who take care of the elderly people in their homes.'' Also, ''We can have a chain of relationships where people in the villages can go through their elders or whoever oversees the National Health in their village through that to the political ward. Then the local governments, I think that will be the easier way for people to access it.''* (Mal, 73-years old).

Furthermore, suggestions and views shared by some of the policy implementers suggest the necessity to have a structure for channelling resources based on the needs of the beneficiaries.

> *''Resources for caregivers will be channelled directly to family caregivers, via their bank accounts* or *rather to reliable persons or agencies such as non-governmental organisations that support the elderly*.'' (Dosh, 55-years old).

> *If there is any support, we link up with social welfare officers or other NGOs that can support the elderly. When people support and realise it is channelled appropriately, they want to give more''.* (Sule, 53-years old).

Trust in leaders

Majority of the discussants expressed that people do not trust leaders when it comes to resource provision and allocation for the elderly and their caregivers or representatives. Community and religious leaders unanimously expressed that there are people and organisations willing to support family caregivers if they trust that tangible and financial resources provided will reach targeted group of persons. Whilst the challenge in supporting family caregivers, some of the religious leaders reveal that there exist some organisations that want to support.

> *"Some NGOs want to support us, but what they give does not reach the suffering people. It ends up in the hands of others, those whom NGOs send to support family caregivers.*'' (Ate, 62-years old).

Awareness creation

Majority of respondents revealed that people are not aware of the significant role that family caregivers play in caring for older adults with chronic illness. Therefore, their knowledge and understanding on the importance of supporting family caregivers is lacking.

> *''I cannot see anybody keen on supporting family caregivers. Our people are not used to that; everybody is left to his fate. They do not even know these people exist. You need time to convince people that the community around should help caregivers and the elderly.''* (Ima, 80-years old).

Some of the participants acknowledged efforts regarding awareness creation. Participants highlighted the importance of raising awareness among the public, particularly in the communities and amongst organisations that can support family caregivers.

> *''First thing is we organise lectures, and call people. To create awareness that there is the elderly in our society. Some people do not even know that the elderly exist and that these are their needs, and they need care from people.''* (Isa, 65-years old).

Continuity and sustainability

A final sub-theme addressed in the second theme was continuity and sustainability of support to family caregivers. Most of the participants were concerned about the availability of funds and the challenges involved in raising funds to continuously sustain interventions. Policy implementers talked about some of the activities that were held in the past in support of older adults and their families. However, despite policy implementers carrying out some sensitization activities in the past, they are unable to continue due to financial constraints. This reveals the inability to sustain activities and for awareness creation due to lack of funds.

> *'In 2020 we did sensitization on the need to support the elderly in their communities. Unfortunately, for some time now because of the economic crunch in this state we have not be able to do.''* (Akoso, 49-years old).

The continuity and sustainability of supporting family caregivers depends on awareness creation, donor intervention, government budget lines, and family participation.

Theme 3: The positive impact of supporting family caregivers.

Our study revealed positive impact of supporting family caregivers. Majority of the discussant expressed how support from people can make a significant difference in the lives of caregivers. The meagre support can go a long way to put a smile on the faces of caregivers and makes the patients happy. It is also an encouragement to caregivers to go on caring for their loved ones who are sick.

Just a little support makes a difference

Both community and religious leaders expressed that nothing is too small to give, no matter how meagre the support, it will be of help to a caregiver. According to some of the participants in the support group it will encourage caregivers' outcome. Some of the respondents shared that support could be financially, providing medication, food, appreciating their efforts, and the ability to cope with the burden of care. Especially if the support meets the needs of the caregivers and care recipient.

> *''The impact of the support will go a long way if all the factors behind the situation are understood because the support must take cognisance of every dynamic that is part of the challenge at hand.''* (Anon, 67-years old).

Mitigate guilt, worry and anxiety

Policy implementers suggest that '' Even if the support is little it will be helpful to mitigate guilt, worry and anxiety amongst caregivers. Some participants revealed that caregivers of the experience guilt and are worried about the patient's condition, thinking what could happen to the older adult when left alone. Findings indicate that the more the caregiver experiences anxiety and worry the greater their inability to care.

> *'' If they have the support in terms of money, materials and so on to look after the elderly that will reduce the burden of worry anxiety, invariably that will promote a better way of life, prosperity safe way of life, and of course have time to do other things''* (Dosh, 55-years old).

Stakeholder collaboration and partnership

To create impact when supporting family caregivers, majority of the respondents suggested inter-relationship between family caregivers and other sources of the social support network apart from family and friends. This may include non-governmental organisations, community leaders, religious leaders, and government. Some of the participants recommended all types (emotional support, informational support, tangible support, and social companionship) of support to promote wellbeing of caregivers. Also, majority of the participants suggested the need for stakeholder collaboration and partnership.

'' The elderly healthcare policy in Nigeria is dependent on traditional communal lifestyle. Thus, my suggestion is that government at the federal level should try and partner with some like-minded people to work out modalities around an elderly care policy'' (Akoso, 49-years old).

''Another dimension or model that other people are using now is to work with communities through the development of community support groups where members of families who have an elderly with them can come together as a support group and then they undertake economic activities together'' (Dosh, 55-years old)

'' We can approach other philanthropist or even non-governmental agencies or even churches to support this project'' (Terabaa, 59-years old).

Discussion

This article presents the perception of policy implementers, healthcare professional, religious and community leaders on the need to support family caregivers of older adults with chronic illness at home. Our data indicate that family caregivers are situated in the background or context of caregiving, often as mere family members or objects and less frequently as agents with influence in patient care. Through interviews all respondents recognize the need of a social network which forms the structural component of social support for family caregivers, which is consistent with previous studies (Nolan, 2001). Similarly, a study by Reinhard et al, (2019) and Feinberg et al, (2011) suggest formally recognising family carers as 'care recipients;' and to include support for family caregivers in budget lines for future planning and decision making by statutory and voluntary bodies. This will help to justify the need for resource allocation and for sustainability of activities targeted to supporting family caregivers (Feinberg et al., 2011; Reinhard et al., 2014).

The purpose of this study was to understand better how relevant stakeholders such as policy implementers, healthcare workers, religious leaders, and community leaders see support for family carers. The study showed that there hasn't been much effort put into raising awareness of and understanding the crucial part family caregivers play in the unofficial healthcare system. This affects the function of caregiving and the accessibility of support services. When examining caregiving for older individuals with chronic illnesses, the perspectives of patients, family caregivers, and healthcare professionals are infrequently considered (Gill et al., 2014; Kuluski et al., 2013). However, no studies have looked at the interactions between family caregivers, healthcare workers, religious leaders, community leaders, policy implementers, and senior citizens with chronic illnesses. Most of the research articles concentrated on the significant role the government may play in supporting carers in families. However, none of the studies has mentioned the perspective of other stakeholders. The idea of a family caregiver support network has not yet been considered in the Nigerian setting. The views of family carers of elderly individuals with chronic illnesses have not been studied in the central region of Nigeria; only the south-western region (Oyo and Osun), south-southeast (Enugu), and south-south (Cross-River) have done so.

According to the data presented, ineffective resource allocation, ignorance, a lack of confidence in leadership, and a lack of initiatives and plans for continuity and sustainability could limit support for family caregivers in Nigeria. Therefore, it is necessary to raise awareness through a variety of public channels, including lectures and religious meetings, to inform people about the essential role of the public in the crucial function of family caregivers and the burden of care they bear. This suggests that other stakeholders' contributions to spreading knowledge about family caregiver assistance in Nigeria are essential. To accomplish this, the government should be in the lead as the body responsible for making and implementing decisions. Stakeholders including families, community leaders, religious figures, and community organisations can also formally raise awareness. Both community leaders and religious leaders reported the need to first identify family caregivers and their needs to be able to support them. Without both groups in place, it will be difficult to formerly organised any formal intervention to support family caregivers.

Through interviews the study highlighted the significance of partnership between family caregivers, policy implementers and other stakeholders to support family caregivers. Explaining further, some respondents suggest all hands be on deck, as family and friends supporting family caregivers alone is not enough. Both government, community (clan heads, community leaders), and others (foundations) have a role to play. According to the support network's findings, religious organisations play a crucial role in mobilising resources, locating family carers, and efficiently distributing these resources. The study's results are in line with those of (Akpan-Idiok et al., 2020; Adedeji et al., 2022), which highlighted the significance of cooperative obligations on the part of the state, non-governmental organisations, and other support groups.

In addition, the results of the current study strongly imply that if they choose to, the government is best placed to lead the effort to promote support for family caregivers. Some family caregivers, however, have little to no faith in the government, according to data gathered. Findings imply that public servants are corrupt and inaccessible. As a result, even if resources are made available, they will not be effectively distributed. It is still up for debate to what extent the government should get involved in helping carers. Some local officials claimed that although some individuals wish to donate, they are unsure if it will reach the intended recipients. But maybe people won't be sceptical of government assistance if there is trust in both the resource distribution and leadership modes. Participants claimed that they do not see the money and that the money ends up in the hands of others. In accordance with these discoveries, Lambert and Girgis (2017) state that trust is a crucial component of successful interventions. Caregiver support services must be valued by caregivers for them to be effective. They must also believe the intervention is appropriate for the caregivers' circumstances and have faith in the people giving it (Lambert and Girgis, 2017).

Furthermore, continuity and sustainability of support for family caregivers is a challenge faced by some stakeholders that have activities and interventions planned. However, policy implementers advise relying on raising awareness, getting help from donors, using government funds, and involving as many stakeholders if there will be continuity and sustainability. According to the study's findings, donors significantly contribute to the consistency and sustainability of support for family carers. However, benefactors typically only sponsor a project for a specified amount of time. The government is consequently accountable for having budget lines for continuity and sustainability. For funds to be raised towards support of family caregivers, other stakeholders who wish to contribute can do so without difficulty. Therefore, it is essential to raise public awareness of family caregivers, their needs, and the opportunities that are accessible. Results also showed that sustainability and continuity depend on the resources that are available. Findings reveal that efforts by government in organising programmes targeted to support older adults and their families can be sustained if the source of resource allocation is consistent with plans and interventions towards support for families of the elderly. However, from a few of the respondents, it evident that even the activities mentioned—those run by the government and NGOs—were targeted at helping elderly people in the state, not necessarily family caregivers. Therefore, it is crucial to have a support system directed to family caregivers. This is in line with earlier studies (Reinhard et al., 2019; Reinhard et al., 2008) that recommended having resource allocated for family caregiver pertinent to their needs.

As a result, helping family carers could lessen feelings of guilt, concern, and anxiety if the right resources are directed toward them. This will invariably lead to the caregiver having a better quality of life. Similar conclusions are drawn from previous research (Losada-Baltar, 2016; Cooper et al., 2008). Leaders from the community and the religious community agreed that there is no amount of help too small for family carers. Some support group members remarked that the caregiver will benefit greatly from any assistance, no matter how small. The carers will be inspired to exert greater effort regardless of the type or amount of help provided, even if it is minimal. In addition, other studies (Michael et al., 2016) report that sharing their experiences can create awareness about the importance of supporting family caregivers and inform interventions. Despite the lack of support towards family caregivers, respondents reveal that people are willing to provide support if there is enough genuine and transparent information regarding the family caregivers and the channel of resource distribution.

Study Limitations

This study represents the experiences of purposively selected policy implementers, healthcare professional, community, and religious leaders in Benue, Nigeria. Due to the limited number of a support network, it is not possible to generalize the findings to other population groups. Hence, it is worthy for similar research to be conducted in other states of Nigeria and African regions. Also, participants in the current study may not be the only stakeholders that are available to support family caregivers. Therefore, there is a need to extend further studies to capture other relevant stakeholders that could have a role to play in supporting family caregivers. Nevertheless, the findings of this study stand to be fundamental to policy makers and all relevant stakeholders that can play a significant role in supporting family caregivers in Nigeria.

Conclusion

This research explores the perception of policy implementers, healthcare professionals, community, and religious leaders on support for family caregivers of older adults with chronic illness at home in Benue state, North Central region of Nigeria. In the absence of inadequate policies and lack of implementation of the existing policies on older adults' care, families and communities tend to provide support in terms of services to the older adults to address the gap in formal policy. Family caregivers of elderly persons with chronic conditions play a vital role in promoting well-being among older adults with chronic illnesses and therefore need support, which is mostly given by family members and friends. Nevertheless, support by family and friends is not enough to ameliorate the burden experienced by caregivers. Hence, collaboration by relevant stakeholders such as government organisations at all levels, non-governmental organisations, community, and religious leaders is suggested. The findings underscore the importance of collaborative participation of different stakeholders. This implies that the roles of other stakeholders are significant in the action to create awareness about support for family caregivers in Nigeria. Hence, government as the decision making and implementing body, should be at the frontline to achieve this. Other stakeholders mentioned above can also informally increase awareness through various means which can lead to accessible support programs to improve health outcomes for family caregivers. To achieve these, deliberate efforts should be made to identify both family caregivers and stakeholders to collaborate. These processes can facilitate replication in future research and inform practice, programs, and policies.

Recommendation

This study might be considered a pioneering investigation into the need for family caregiver support in Nigeria. The results of this study, however, indicate a limited sample size, as noted in the section of the article that discusses limitations. Nevertheless, future studies should delve more into the precise requirements of family caregivers and the potential for pertinent parties to play roles in supporting family caregivers. Support for family caregivers is currently at an all-time low. This report advises key stakeholders to form partnerships. They comprise all tiers of government, non-governmental organisations, neighbourhood, and religious groups. Therefore, it is proposed that key players collaborate to create workable and accessible support programmes that can help family caregivers. Evidence suggests that family carers' quality of life may be improved by encouraging cooperation between interested parties and providing support. A strategy that should incorporate and engage the entire community is to start awareness campaigns in churches, mosques, and community support organisations. Participants in the study might also start a caregiver support group in their local area. On the other hand, the church can organise its members as volunteers who are able and eager to spread the word about family caregiver support. To help family caregivers effectively, stakeholders should consider local and culturally specific initiatives.

Statement and declaration

The authors declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Conflicting interest

The author(s) received no financial support for the research, authorship and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship. And/or publication of this article.

References

Adebusoye, L. A., Ladipo, M. M., Owoaje, E. T., & Ogunbode, A. M. (2011). Morbidity pattern amongst elderly patients presenting at a primary care clinic in Nigeria. *African Journal of Primary Health Care & Family Medicine*, *3*(1), 21-26. https://hdl.handle.net/10520/EJC134151

Adedeji, I. A., Ogunniyi, A., Henderson, D. C., & Sam-Agudu, N. A. (2022). Experiences and practices of caregiving for older persons living with dementia in African countries: A qualitative scoping review. *Dementia*, *21*(3), 995-1011. Online publication. https://doi.org/10.1177/14713012211065398

Adewuya, A. O., & Oladipo, E. O. (2020*).* Prevalence and associated factors for suicidal behaviours (ideation, planning, and attempt) among high school adolescents in Lagos, Nigeria. *European Child & Adolescent Psychiatry journal*, *29*(11), 1503-1512. https://doi.org/10.1007/s00787-019-01462-

Agrawal, G. J. (2013). *Burden among caregivers of mentally ill patients: A rural community-based study*. *International Journal of Research and Development of Health*, *1*(2), 29-34. https://citeseerx.ist.psu.edu/document?repid=rep1&type=pdf&doi=29dbe17c150ffe053c6f35a82a230172cab794cb

Akanji, B. O., Ogunniyi, A., & Baiyewu, O. (2002). Healthcare for older persons, a country profile: Nigeria. *Journal of the American Geriatrics Society*, *50*(7), 1289-1292. https://doi.org/10.1046/j.1532-5415.2002.50319.x

Akpan-Idiok, P. A., Ehiemere, I. O., Asuquo, E. F., Chabo, J. A. U., & Osuchukwu, E. C. (2020). Assessment of burden and coping strategies among caregivers of cancer patients in Sub-Saharan Africa. *World Journal of Clinical Oncology*, *11*(12), 1045. https://doi.org/10.5306/wjco.v11.i12.1045

Asuquo, E., Etowa, J. B., & Adejumo, P. (2013). Assessing the relationship between caregivers' burden and availability of support for family caregivers of HIV/AIDS patients in Calabar, south east Nigeria. *World Journal of AIDS*, *3*(4), 335. https://doi.org/10.5306/wjco.v11.i12.1045

Faronbi, J. O., Ajadi, A. O., & Gobbens, R. J., Institute of Neuroscience and Physiology, Göteborgs universitet, Gothenburg University, Sahlgrenska Academy, Sahlgrenska akademin and Institutionen för eurovetenskap och fysiologi (2020). Associations of chronic illnesses and socio-demographic factors with health-related quality of life of older adults in Nigeria: A cross-sectional study', *Ghana Medical Journal*, 54(3), pp. 164. https://doi.org/10.4314/gmj.v54i3.7

Faronbi, J. O., Butcher, H. K., & Olaogun, A. A. (2019). Burden and coping ability of individuals caring for chronically ill older adults in Nigeria: A mixed methods study. *Journal of Gerontological Nursing, 45*(1), 39-46. https://doi.org/10.3928/00989134-20190102-06

Faronbi, J. O., Faronbi, G. O., Ayamolowo, S. J., & Olaogun, A. A. (2019). Caring for the seniors with chronic illness: The lived experience of caregivers of older adults. *Archives of Gerontology & Geriatrics, 82*, 8-14. https://doi.org/10.1016/j.archger.2019.01.013

Feinberg, L., Reinhard, S. C., Houser, A., & Choula, R. (2011). Valuing the invaluable: 2011 update, the growing contributions, and costs of family caregiving. *Washington, DC: AARP Public Policy Institute, 32, 1-28*. https://doi.org/10.1016/j.archger.2019.01.013

Fernandes, C. S., & Angelo, M. (2016). Family caregivers: What do they need? an integrative review. *Revista Da Escola De Enfermagem Da USP, 50*, 675. https://doi.org/10.1590/S0080-623420160000500019

Goldberg, A., & Rickler, K. S. (2011). The role of family caregivers for people with chronic illness. *Rhode Island Medical Journal, 94*(2), 41. http://rimed.org/medhealthri/2011-02/2011-02-41.pdf

Kaschowitz, J., & Brandt, M. (2017). Health effects of informal caregiving across Europe: A longitudinal approach. *Social Science & Medicine, 173*, 72-80. https://doi.org/10.1016/j.socscimed.2016.11.036

Kogan, A. C., Wilber, K., & Mosqueda, L. (2016). Person-centred care for older adults with chronic conditions and functional impairment: A systematic literature review. *Journal of the American Geriatrics Society, 64*(1), 1-7. https://doi.org/10.1111/jgs.13873

Lambert, S. D., & Girgis, A. (2017). Unmet supportive care needs among informal caregivers of patients with cancer: Opportunities and challenges in informing the development of interventions. *Asia-Pacific Journal of Oncology Nursing, 4*(2), 136. https://doi.org/10.4103/2347-5625.204485

Lee, J., Baik, S., Becker, T. D., & Cheon, J. H. (2022). Themes describing social isolation in family caregivers of people living with dementia: A scoping review. *Dementia, 21*(2), 701-721. https://doi.org/10.1177/14713012211056288

Lim, J., & Zebrack, B. (2004). Caring for family members with chronic physical illness a critical review of caregiver literature. *Health and Quality of Life Outcomes*, *2*(1), 50. https://doi.org/10.1186/1477-7525-2-50

Michael, S. N., Emmanuel, A. E., Aliyu, D., Salga, M. A., & Saleh, A. B. (2016). Public awareness and perception on care for the elderly among Funtua residents in katsina state, north-west Nigeria. *World*, *4*(1), 20-24. https://doi.org/10.12691/jpm-4-1-4

Nolan, M. (2001*). Working with family carers: Towards a partnership approach*. *Reviews in Clinical Gerontology*, *11*(1), 91-97. https://doi.org/10.1017/S0959259801011182

Noreen, N., Abdullah, M., & Lalani, N. (2021). Geriatric care in Pakistan: Current realities and way forward. *Pakistan Journal of Public Health*, *11*(4), 214-219. https://doi.org/10.32413/pjph.v11i4.872

Ojagbemi, A., Bello, T., Luo, Z., & Gureje, O. (2016*).* Chronic conditions, new onset, and persistent disability in the Ibadan study of aging. Journals of Gerontology Series A*: Biological Sciences & Medical Sciences*, *71*(4), 997–1005. https://doi.org/10.1093/gerona/glv188

Ojifinni, O. O., & Uchendu, O. C. (2022*).* Experience of burden of care among adult caregivers of elderly persons in Oyo state, Nigeria: A cross-sectional study. *The Pan African Medical Journal, 42, 64* *https://doi.org/10.11604/pamj.2022.42.64.32715*

Okediji, P. T., Ojo, A. O., Ojo, A. I., Ojo, A. S., Ojo, O. E., & Abioye-Kuteyi, E. A. (2017). The economic impacts of chronic illness on households of patients in Ile-Ife, south-western Nigeria. *The Pan African Medical Journal*, *9*(10) https://doi.org/10.7759/cureus.1756

Reinhard, S. C., Feinberg, L. F., Houser, A., Choula, R., & Evans, M. (2019). Valuing the invaluable: 2019 update charting a path forward. *AARP Public Policy Institute. Retrieved July 19, 2023, 146, 1-32.* *https://outlook.office.com/mail/sentitems/id/*

Reinhard, S. C., Levine, C., & Samis, S. (2014). Family caregivers providing complex chronic care to their spouses. *Washington, DC: AARP Public Policy Institute. Retrieved July 19, 2023, 14, 1-10.* *https://www.giaging.org/documents/family-caregivers-providing-complex-chronic-care*

Sit, J. W., Wong, T. K., Clinton, M., Li, L. S., & Fong, Y. (2004). Stroke care in the home: The impact of social support on the general health of family caregivers. *Journal of Clinical Nursing, 13*(7), 816-824. https://doi.org/10.1111/j.1365-2702.2004.00943.x

Son, J., Erno, A., Shea, D. G., Femia, E. E., Zarit, S. H., & Parris Stephens, M. A. (2007). The caregiver stress process and health outcomes. *Journal of Aging and Health, 19*(6), 871-887. https://doi.org/10.1177/0898264307308

Stoltz, P., Uden, G., & Willman, A. (2004). Support for family carers who care for an elderly person at home–a systematic literature review. *Scandinavian Journal of Caring Sciences, 18*(2), 111-119. https://doi.org/10.1111/j.1471-6712.2004.00269

Victor, O. U. (2008). Ageing and urban–rural drift in Nigeria: Coping or dispensing with city accommodation in retirement. *Ageing Research Reviews, 7*(4), 275-280. https://doi.org/10.1016/j.arr.2008.02.002

Zarit, S. H., & Zarit, J. M. (2015). Family caregiving. *Psychology and geriatrics* (pp. 21-43). Elsevier.