

Factors militating against the preparedness of families in managing terminal health conditions in Nsukka, Enugu State, Nigeria

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ABSTRACT

The family is an integral part of society that is assigned enormous responsibilities, especially with the care of its members both children and adults. Terminal health conditions do not just affect the individuals involved but the entire family; therefore, when a family member is sick, the entire family is sick. This study aimed to interrogate the factors militating against families' preparedness to manage the terminal health conditions of their members. Using in-depth interviews, data were collected from 13 families in Nsukka that were randomly selected for the study. The inclusion criteria were that the participant must be an adult member of a family who has taken or currently taking care of a terminally ill patient/family member. The interviews were transcribed and coded accordingly, and the data were analyzed using inductive thematic methods which helped to extract participants' chronological experiences in caring for terminally ill family members. The results show that families and caregivers face chronic stress and exhaustion when caring for their terminally ill members. Participants reported pressure and socio-economic challenges as factors affecting the management of family members with terminal health conditions. The study has implications for social work and other service-based professionals in healthcare. It calls for the design of holistic care interventions, involving both the patients and family caregivers. The study also draws attention to the need to revitalize palliative care services at every level of the healthcare delivery system in Nigeria with options for home services.

Keywords: family preparedness, terminal health condition, palliative services, social work

Introduction

The family has the primary responsibility of providing care for her members both in health and sickness. Family caregiving connotes the provision of assistance, mostly unpaid, by relatives, friends, partners, or neighbors to an individual who is unable to care for himself/herself independently due to illness, or limitation in their body functioning (Schulz et al., 2020; Ferrell et al., 2018). Globally, there is a rising rate of chronic diseases confronting

individual members of the family; and the family system has been stretched attempting to provide care for their ill members (Kokorelias et al., 2019; Umeifekwem & Okoye, 2023). The situation is more precarious when families are to provide care progressively to their terminally ill members; a situation that comes with diverse manifestations of physical, psychological, social, and spiritual challenges. Terminal health condition according to Guerrero (2011) is an “illness or disease process that is not responsive to curative medical treatment and which will worsen and eventually cause death”. Oftentimes, in caring for terminally ill patients, the emphasis is usually on the affected patients of terminal disease, with a limited attempt at exploring how families caring for terminally ill members are prepared for it (Breen et al., 2018). In traditional care arrangements, the family is central to caring for ailing members both old and young, and provides the necessary materials needed to improve health outcomes and the quality of livelihood of members. Managing terminally ill patients is burdensome, especially dealing with the reality that the patient is being prepared for death; this is not an easy experience for families and caregivers who face various forms of physical and psychological challenges. Breen et al., (2018) argued further that there is a need to look at the preparedness of family caregivers not just in terms of caring for the ailing family member, but most importantly after such patients have passed on. No family caregiver will be comfortable knowing that the person being cared for is billed to die, a situation Cockle-Hearne et al., (2021) referred to as “bereaved-to-be-family; therefore, understanding the post-death preparation of families is an important aspect of palliative care. Comprehensive palliative care as advocated by the World Health Organization (WHO, 2018) entails the provision of services and care that relieve and prevent suffering in both adults and children affected with life-threatening or terminal health conditions and their families. Palliative care aims to improve the quality of life of patients and families through the provision of physical care, medical support, practical help, and emotional and spiritual support (WHO, 2020). It is estimated that each year 56.8 million people, including 25.7 million in the last year of their life need palliative (WHO, 2020). In terminal ill care management, both the patients and the family caregiver have needs such as spiritual needs, socio-economic needs, healthcare needs, etc, that must be accomplished to make care intervention successful (Kim et al., 2020).

In Nigeria, the management of terminal health conditions is a complex and challenging undertaking for many families. Despite the high incidence of terminal health conditions in Nigeria, various factors militate against the preparedness of families to effectively manage these conditions. Akpan et al., (2020) opined that inadequate support from the public health system, misconceptions and stereotypes surrounding terminal health conditions, and limited access to reproductive health services all contribute to the challenges

faced by families in managing terminal health conditions in Nigeria (Akpan et al., 2020; Iweama et al., 2021). Inadequate health facilities and structures, corruption in the system, poor management of human resources, and poor motivation and remuneration of healthcare workers are some of the reasons advanced (Obum & Kelana, 2023; Ogunbamila, 2014; Akinwumi et al., 2022; Akokuwebe & Idemudia, 2022; Agom et al., 2020). Many health facilities in Nigeria do not have a functional palliative care unit, and where they exist, it is not well equipped and manned by enough relevant professionals (Haines, 2018). Highlighting their effects, Iweama et al., (2021) opined that these factors collectively contribute to a weakened and fragile healthcare system in Nigeria, making it difficult for families to access the necessary support and resources for managing the terminal health conditions of their members.

Misconceptions and stereotypes contribute to stigma and discrimination and are capable of hindering families' access to appropriate healthcare services and support (Mekonnen et al., 2020; Sarki & Roni, 2019). Evidence from studies has shown that there may be beliefs that terminal health conditions are punishments or divine retribution, and this leads to a reluctance to seek medical treatment by families (Mekonnen et al., 2020; Sarki & Roni, 2019). In addition, Envuladu et al., (2021) submitted that limited access to reproductive health services in Nigeria further exacerbates the challenges faced by families in managing terminal health conditions. Women face various forms of barriers to accessing reproductive health services, such as lack of availability, affordability, and cultural or social barriers (Envuladu et al., 2021; Kamimura, 2018). Many terminal health conditions such as breast and cervical cancer have made women vulnerable. These barriers prevent women from receiving timely and appropriate screenings, diagnosis, and treatment for terminal health conditions like breast and cervical cancer (Gakunga et al., 2019).

According to Ameh et al., (2021), the high cost of healthcare services affects timely and appropriate care, leading to delays in diagnosis and treatment, as well as poor disease management. Importantly, many chronic illnesses require huge capital to be adequately managed; in fact, the relapse to the terminal condition of these diseases was a result of a lack of adequate resources to treat them at the onset. Using the case of cancer, huge resources are usually needed to manage the disease right from the diagnosis stage through to treatment and radiotherapy (Ferrell et al., 2022). Therefore, the high cost of healthcare services in Nigeria poses a significant barrier to families in managing terminal health conditions (Ameh et al., 2021; Adegoke et al., 2022). In most cases, the family caregivers are children whose parents are terminally ill, and adequate support systems will help improve their coping capacities especially when such children are still dependent (Cockle-Hearne et al., 2021). Anderson et al.,

(2019) advocated that effective communication between families of terminally ill patients and healthcare professionals are essential intervention mechanisms for reducing the impact of the condition on the family caregivers. A terminally ill patient faces imminent death and proper communication between the family and healthcare management team may create a pathway for happy death and grief management.

Social work professionals are an integral part of palliative care and successful chronic care interventions for families of terminally ill patients (Taels et al., 2021). Palliative care takes a multidisciplinary team approach to holistically manage terminal health conditions or end-of-life care plans for the patients and their family caregivers (Agha et al, 2022). A 2004 report by the National Association of Social Workers (NASW) indicated that the social worker irrespective of area of practice or specialty has the ethical responsibility to work with clients facing acute and life-threatening conditions. Social workers form a key part of the multidisciplinary team and have enormous responsibilities to contribute to the healthy caring of patients with terminal illnesses (Okoye, 2019). However, Taels et al., (2021) opined that social work professionals are often inadequately represented in palliative care although terminal health care has social implications. The social work professional plays various roles in terminally ill patients including psychological assessment, care coordination, crisis intervention, counseling and psychotherapy, patient education, and resource navigation services (NASWS, 2010; Agha et al., 2022). In Nigeria, social workers have not gained enough ground in terms of specialization, however, the services are provided by medical social workers employed in hospitals mostly tertiary hospitals (Okoye, 2019). Providing services to terminally ill patients and their families can be challenging for social workers due to socio-cultural factors, Okoye (2019) opined that death is not discussed in Nigeria as there are beliefs that doing so may bring it to reality, hence, religious leaders are collaborated with in the process.

Various studies have been conducted to address different aspects of family experiences about caring for or managing terminally ill members' conditions. For instance, Anderson et al (2019) investigated communication patterns between healthcare professionals and family members; Cockle-Hearne et al, (2021) made an argument for support interventions for children of parents with a terminal health condition; Breen et al. (2018) studied family caregivers' preparation for death; while Ferrell et al. (2022) argued for developing educational interventions for managing symptoms. Other studies include that of Kim et al (2020) who compared the spiritual needs of patients with terminal kidney disease and family caregivers; Banjarnahor (2019) explored the relationship between family readiness and quality of life of patients with a terminal disease; and Haines et al., (2018) who interrogated the barriers in

accessing palliative care for pediatric patients with cancer, amongst other studies. Whereas these aforementioned studies glossed over various aspects of palliative care and family caregivers' experiences, limited studies have attempted to holistically investigate the factors affecting family preparedness to care for terminally ill members, especially in a semi-urban society in Nigeria with social work implications. In light of this seeming shortcoming in literature, this study aims to fill the gap by interrogating the preparedness of family caregivers to provide care to family members with terminal health conditions in Nsukka town and its practice implication for social work practice in Nigeria. It aims to answer the questions of family caregivers' experiences; opposing and supportive factors, and means of overcoming the challenges.

Materials and Methods

Study design and setting

The study adopted the descriptive phenomenological qualitative research design. The research method provided the premises for the exploration of the experiences of family caregivers of patients with terminal health conditions, available support networks, and the militating factors affecting family dispositions to caring for terminally ill members (Holloway & Galvin, 2017; Rodriguez & Smith, 2018). The study was conducted in the town of Nsukka, in the northern part of Enugu State, Nigeria which includes the University of Nigeria community and the Nsukka urban areas. Nsukka is experiencing increased urbanization with attending challenges as more people keep trooping into the town for various forms of engagement including education, work, business, and other formal and informal engagements (Arene & Anyaeji, 2010). Nsukka town plays host to different categories of people especially students due to the presence of the University of Nigeria. Healthcare delivery in Nsukka is done at both orthodox and traditional levels as obtainable in various hospitals and traditional herbal homes within the town. This may explain the reason families patronize any of the healthcare delivery channels in sourcing medical help for their ailing members. The town of Nsukka has a common practice that is obtainable in Igbo society where caring for terminally ill members or conducting their burial at death are capital-intensive venture that requires huge financial spending. For this reason, caring for a family member with terminal health conditions or conducting their burial when they are dead are always worrisome to family members. The choice of the study area was justified to enable the researcher to extract information within available financial resources as the study is self-sponsored, however, the study can also lay the foundation for further studies or expansion of the study area.

Participants recruitment

The participants for this study were adult family members in the Nsukka metropolis who had cared for or currently caring for terminally ill patients. Individuals in this category were considered for the study because it is believed they can meet the study expectations by providing detailed accounts of their family experiences of providing care to terminally ill family members as well as making informed contributions on the inhibiting factors and ways of improvement. Purposive and snowballing sampling were used in the selection process of the participants. The researcher made constant visits to key healthcare centres in the town including the University of Nigeria Medical Centre, Bishop Shanahan Memorial Hospital, and Faith Foundation Hospital, as well as relied on referrals from community members who knew of family members living with or who died of a terminal illness. This helped to recruit participants used for the study. The recruited participants were properly informed of the objectives, benefits, and risks of participating in the study before they were engaged, and they provided their informed consent to participate in the study. They were fully assured of confidentiality of every information provided, and that they have a right to withdraw from the study at any time if they feel so. A total of 22 family members who met the criteria were approached, however, nine of them declined to participate leaving 13 that were used for the study.

Methods of data collection

Primarily, the in-depth interviews [IDIs] were used to collect data for the study, aided by the instrumentality of a semi-structured interview guide. The use of IDI was preferred to other forms of qualitative methods of data collection and it was necessitated by the need to obtain direct, focused, insightful, and complex information on family experiences in caring for terminally ill members. There was also the consideration that bringing the participants at the same time for focus group discussion (FGD) would not yield the expected results as the participants were not situated in the same environment, and the financial requirement for mobilizing them was a constraint. The interviews were conducted flexibly at the participants' preferred location and language (English or Igbo), and each interview lasted between 35 - and 40 minutes. Using the interview guide, the processes were solely moderated by the researcher while also taking notes and making appropriate observations.

Data analysis

The data collected through the IDIs were analyzed using the inductive thematic approach. The audio-recorded interviews were transcribed along with field notes, and manually coded to extract from the transcripts, participants' recurrent points concerning the key areas of the study (Williamson et al, 2018). The interview transcripts were read several times to familiarize and gain a good understanding, highlighting key themes. The

manually generated codes from the transcripts were shelved and potential themes were extracted which was further reviewed to ensure their relationships with the initial codes. Finally, the final report was arranged and done using the themes and subthemes that emerged.

Results

Socio-demographic characteristics of participants

The demographic characteristics of the study participants are shown in the table below:

Table 1: Demographic characteristics of participants

Pseudonyms	Age	Occupation	Sex	Education	Religion	Marital status
Charity	38	Civil servant	Female	SSCE	Christianity	Married
Dubem	54	Civil servant	Male	NCE	Christianity	Widower
Confidence	37	Trading	Female	SSCE	Christianity	Single
Chidiebube	44	Civil servant	Female	Ph.D	Christianity	Married
Vincent	27	Student	Male	Undergrad	Christianity	Single
Ndidi	52	Trading	Female	SSCE	Christianity	Married
Ukamaka	29	Civil servant	Female	HND	Christianity	Married
Kingsley	22	Student	Male	Undergrad	Christianity	Single
Ugwueze	48	Student	Male	MSc	Christianity	Married
Eddy	62	Retired	Male	BSc	Christianity	Married
Queeneth	47	Civil servant	Female	MSc	Christianity	Widow
Justina	33	Civil servant	Female	NCE	Christianity	Married
Adaobi	29	Civil servant	Female	NCE	Christianity	Single

Fieldwork, 2023

From the inductive thematic analysis, three main themes were identified reflecting the participants' views on factors militating against families in caring for terminally ill members. The identified themes are as follows: (1) Family caregivers' experiences (2) Militating factors to caring for terminally ill patients, and (3) Ways of improving care for terminally ill patients. Table 2 shows the themes and subthemes.

Table 2: Presentation of themes and subthemes

Main themes	Sub-themes
Family caregivers' experiences	<ul style="list-style-type: none"> -Physical and psychological pressure - Stress and emotional exhaustion - Fear and uncertainty - Living in denial
Militating factors	<ul style="list-style-type: none"> - Limited material and financial resources - Cultural views around terminal illness - Lack of professional home-based nurses - Rigorous health-seeking pathway and poor palliative services - Lack of community cooperation
Improvement options	<ul style="list-style-type: none"> - Strengthening palliative services - Increased knowledge and awareness - Government interventions - Community orientations

Fieldwork, 2023

From the identified themes and sub-themes, participants' views were presented using excerpts from responses to support the various themes and sub-themes. This is captured below showing the main themes, sub-themes, and qualifying comments from the participants.

Theme 1: Family caregivers' experiences

The participants in responding to the questions shared their individual current or past experiences providing care for terminally ill patients as classified into the sub-themes below.

Physical and psychological pressure

The study participants reported that in caring for the terminally ill, they face both physical and psychological pressure. This assertion was captured in the comment made by one of the participants, thus:

I can't imagine or explain the kind of pressure I was under. You keep hearing one suggestion or the other on what to do and what not to do. When you think you have put in your best but no sign of improvement, it can be tiring (Adaobi 29).

Stress and emotional exhaustion

Various responses from the participants indicated that family caregivers experience stress and emotional exhaustion. Their views are summed in the assertion below:

I don't feel good talking about the whole thing, it is traumatizing. I have been moving up and down trying to provide one requirement

or the other, yet since the time we came here, there is no sign of hope..." (Eddy 62, Male)

Fear and uncertainty

It was deduced from the participants' responses that the entire family and caregivers of terminally ill patients live in fear and uncertainty as to what may happen next. The views shared by two of the participants illustrated this as shown in the excerpts below:

"... I was completely uncertain of what will happen next. I was not sure of anything and fear was around me..." (Charity, 38, female).

"... I was unable to attend to any other thing, I did not go for my business, I was even afraid of leaving the house for a very short time..." (Dubem 54, male).

Living in denial

The participants reported the experiences of living in denial while caring for family members with terminal health conditions. The comment by one of the participants as indicated below summed the shared experiences of the majority of the participants.

To be honest, I never thought of the possibility of losing him through the sickness. He was very sick and it appeared there was nothing else to do after seeking medical attention from various quarters. All hands were pointing to the fact that he would not survive but it was the last thing I would accept until that particular day ..(Queeneth, 47 female)

Theme 2: Militating factors

Participants during the interview sessions provided what they considered to be the challenges or factors limiting families' response to caring for patients with terminal conditions. This forms the sub-themes as presented below:

Limited material and financial resources

In the responses of all the participants, financial challenges were mentioned as among the major factors militating against the family in caring for terminally ill members. The comments by a 48-year-old family caregiver, Ugwueze summed up the views of the participants.

We were drained financially due to the high cost of medical treatment, and you know without money available to care for the sick you would not access quality medical treatment. In our case, money was borrowed, some properties sold... it was a big problem for us..." (Ugwueze, 48, male).

Cultural views

Cultural impediments were extracted from the participants as among the factors militating against families in providing care for family members with terminal illnesses. This reflects the general views of the participants as captured in the excerpt below:

...due to the frailty of my uncle and the fact that he was not improving despite all the treatments, his sickness was attributed to poison. Suggestions were even made to explore other means, and it was in the process that he died (Vincent, 27, male).

Lack of professional home-based nurses

From the responses of the majority of the participants, it was deduced that part of the factors militating against families' caregiving potentials to persons with terminal ill-health is the lack of skilled home-based nurses. This is validated by the summary provided by one of the respondents thus:

... my grandfather had a spinal injury and due to other underlying health conditions, the whole thing became complicated. He later developed sores and my uncles opted for home-based care. The problem was to secure the services professional home-based nurse; all the ones that attended to him were mainly auxiliary nurses ... (Kingsley, 22, male).

Rigorous health-seeking pathway and poor palliative intervention

The participants' responses suggest the challenges associated with seeking healthcare services for their terminally ill relatives. The excerpts below highlighted the views of the participants.

... we have very complex and difficult pathways for seeking health in this country. The time required to respond to medical emergencies and interventions is too long. This is a big problem to many families; imagine taking someone for medical care and spending a whole day or week without any significant progress..." (Chidiebube, 44, female).

"... on top of the stress of providing direct care to patients, I was faced with following up on healthcare providers..." (Confidence, 37, female).

Lack of community cooperation

The participants shared varying views connected to the challenges associated with community support and cooperation towards terminally ill care. The views of the participants are reflected in the comments by two of the participants as follows:

"... The most challenging was the attitudes of people around who were making comments suggestive that my mother is a living dead... (Justina, 33, female).

... People are willing to support you when you are bereaved instead of supporting you when caring for the sick... it seemed as though the death fast-tracked or induced because people look at it as if the patient is punishing the family... (Ugwueze, 42, male).

Main theme 3: Improvement options

The study participants suggested possible ways of improving the care of terminally ill patients and their families. The sub-themes and their corresponding quotes are presented below:

Strengthening palliative services

The sub-theme highlighted participants' views on the need to strengthen palliative care services in the country as a way of improving care provisions and conditions of terminally ill patients. The excerpts below capture the views of the participants

... the experience of attending a hospital and caring for a family member taught me a lot about terminal illness. I learned of palliative care for the first time and when I began to learn more about it, I was surprised. Such services need to be improved to help people in this condition..." (Ukamaka, 29, female). "... I know about palliative care but my family were not convinced... I believe services that attend to patients in these health conditions should be made available and accessible..." (Chidiebube, 44, female).

Increased knowledge and awareness

The need for increased awareness creation and knowledge of both terminal illness and palliative care formed the views of the majority of the participants. The comment below made by one of the participants summed up their views:

... how many people know about palliative care for people with terminal illness, ... caring for them can be burdensome but there are professionals whose job is to adequately care for them but where are they? I think there is an information gap in this matter and there is a need for proper awareness to help families make the best services appropriate for them..." (Queeneth, 47, female)

Government interventions

The participants did not spare the government as a key stakeholder in supporting terminally ill patients and their families to access adequate care and support. A participant summarized the need for government involvement thus:

... families of patients with terminal health go through a lot, and it is all hopelessness. My view is that the government should be involved by making care at this stage highly subsidized or even

free. We spent so much resources in time, money, and energy providing care. Government should intervene to help both the patients and their families to access the needed care..." (Justina, 33, female)

Community education and orientation

Finally, the participants noted that to gain widespread support for terminally ill patients and their families, community involvement is important and that can be achieved through proper community education and orientation about the plights of patients with terminal health conditions. This viewpoint is summed up thus:

"... community orientation is important to make them understand that terminal illness can happen to anybody, it is not witchcraft and those affected should not be abandoned to die shamefully without proper care..." (Adaobi, 29, female).

Discussion

The study interrogated the factors militating against families' preparedness to manage the terminal health conditions of their members. The results as highlighted by the responses of the participants indicated the experiences of family caregivers, the militating factors against family caregiving roles, and mechanisms for improving it. The study results show that family caregivers face various experiences managing the terminal health condition of their members. Such experiences include physical and psychological pressure which manifests as the family members strive to care for ill patients as well as fend for the family and other engagements. The study results also indicated that families are exposed to various forms of stress, depressive experiences, emotional exhaustion, and distortions. These according to the results reflect the experiences of family members as they try to source for a cure or treatment for their ailing members. In addition, fear and uncertainty are part of the experiences faced by family caregivers as the study result spotted. Families of persons with terminal illnesses experience diverse levels of fear and feelings of uncertainty while caring for their sick members. The participants revealed that there is always a clear sense of hopelessness and anxiety over what may happen next. Various studies conducted at different locations have shown that family caregivers face varying experiences caring for terminally ill patients. For instance, Martín et al, (2016) reported that family caregivers of terminal patients experience the physical and emotional burden of care and uncertainty about the future; Choi and Kim (2012) noted the experiences of shock, confusion, and changes in the families, social and personal lives of individuals. Other studies including McFarlane and Liu (2020) revealed the experiences of fatigue, sleeplessness, and confusion in family caregivers; and Ortega-Galán et al. (2019) reported the experiences of suffering, compassion satisfaction, and support. All the findings as espoused

in these studies one way or the other agree with the results of this particular study relating to the experiences of family caregivers.

The study results indicated some of the militating factors against families' preparedness to care. Limited material and financial resources are the factors narrated by the study participants. The study revealed that caring for terminally ill patients requires huge material and financial resources, and that is one of the major factors militating against family preparedness. This finding is akin to the outcome of a study by Ameh et al. (2021) and Ferrell et al. (2022) opined that huge financial and material resources are always needed to properly care for patients with terminal health conditions. Cultural views around terminal illness were highlighted by the participants as a militating factor to family caregivers' response. Okoye (2019) posited that it is culturally unacceptable to discuss someone's death, and this belief may affect the attitude and perception of people within a cultural environment toward terminally ill patients. The study results also indicated that lack of professional home-based nurses, rigorous health-seeking pathway, and poor palliative services constitute part of the barriers hindering family caregiving abilities for terminally ill patients. A study by Cheung et al. (2020) highlighted the unpreparedness of healthcare professionals and the health system in advanced care planning. The study results added that lack of or poor community partnership constitutes a militating factor in family caregiving roles.

On ways of improving health outcomes and family preparedness to care for terminally ill members, the study results revealed that strengthening palliative services and increasing knowledge and awareness are key. This result was boosted by a study conducted by Doobay-Persaud et al. (2023) which reported poor palliative awareness, knowledge, and practice in low and middle-income countries like Nigeria, and the need to strengthen the practice via increased knowledge. Results also indicated that government interventions at all levels of governance are needed to improve family care for terminally ill patients. Agha et al. (2022) argued that a lack of political will on the part of the government contributed to the advancement to the terminal stage of cancer in Nigeria. Therefore, government interventions via protective and preventive regulations, social safety nets for families of terminally ill patients, and health promotions will help improve the management of terminal health conditions in Nigeria. Finally, the study findings revealed the need for community education and orientation as a means of improving terminal health care. An intervention study conducted by Aoun et al (2020) noted that community interventions are key to terminal ill health care, and that community-led models of social and practical support for persons with advanced illness are internationally advocated.

Implication to Social Work Practice in Nigeria

The principles, values, and ethics of the social work profession are clear statements that define how professionals engage with clients. The principles of acceptance and non-judgmental attitudes as well as the values of service, dignity, and worth of the person provide the ethical base for social work intervention for terminally ill patients and their families (Uzuegbu et al., 2017). In the past, most of the challenges attributed to social work intervention in Nigeria were the non-professionalization of the profession due to its legal status. However, the recent signing of the social work professionalization law has foreclosed that challenge, leaving behind another challenge. There is an urgent need for social workers in Nigeria to organize themselves and maximize the legal opportunities available to them including the streamlining of various areas of specialization including palliative care services. In Nigeria, palliative services are provided by the general medical social workers, and not palliative care social workers (Okoye, 2019), and they tend to struggle to adequately provide the services (Taels et al., 2021). Social workers are critical to effective services to terminally ill patients, especially in a multidisciplinary care approach to meet the multidimensional needs of the patients and their families (Taels et al. 2021). For patients with terminal health conditions and their families, social workers can provide them with support services that enhance the quality of life of terminally ill patients. Social workers empower and advocate for the needs and rights of patients in end-of-life palliative care (NASW 2010). Social workers perform case management and navigation as well as providing counseling services and psychosocial assessment of both terminally ill patients and their families (Browne, 2019). Therefore, in caring for patients with terminal health conditions in Nigeria, social workers have enormous ethical responsibilities to perform.

Conclusion

This study identifies factors hindering family caregivers' preparedness to care for terminally ill patients in Nsukka. From the perspectives of the family caregivers who participated in the study, family caregivers' experiences, militating factors, and ways of improving care for terminally ill patients were identified. The participants' responses were related to physical and psychological pressure; stress and emotional exhaustion; fear and uncertainty; and living in self-denial. The participants' responses also related to the barriers: limited material and financial resources; cultural views; lack of professional home-based nurses; rigorous health-seeking pathway and poor palliative services; and lack of community partnership. Other related areas of improvement include the need to strengthen palliative services; increase knowledge and awareness; government interventions, and drive community education and orientation. Families caring for terminally ill patients need concrete interventions to help mitigate the poor outcomes they are being confronted with. Both formal and informal support systems should be

activated within healthcare facilities to enable favourable conditions for care provisions. There is a need to raise social workers' capacity to adequately meet their roles in supporting families of patients with terminal health conditions. Therefore, palliative care services need to be revitalized at both the hospital and home base settings, and trained specialists including social workers engaged to drive the service delivery.

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