



Exploring The Challenges Faced by Informal Home Based Palliative (HBP) Caregivers in Ndola District, Zambia.

Katentemuna Catherine Musonda, Mathew Nyashanu, Wilbroad Mutale, Doreen Sitali & Oliver Mweemba

To cite this article: Katentemuna Catherine Musonda, Mathew Nyashanu, Wilbroad Mutale, Doreen Sitali & Oliver Mweemba (2021): Exploring The Challenges Faced by Informal Home Based Palliative (HBP) Caregivers in Ndola District, Zambia., Journal of Social Work in End-of-Life & Palliative Care, DOI: [10.1080/15524256.2021.1976351](https://doi.org/10.1080/15524256.2021.1976351)

To link to this article: <https://doi.org/10.1080/15524256.2021.1976351>



© 2021 The Author(s). Published with license by Taylor & Francis Group, LLC.



Published online: 06 Oct 2021.



Submit your article to this journal [↗](#)



View related articles [↗](#)



View Crossmark data [↗](#)

Exploring The Challenges Faced by Informal Home Based Palliative (HBP) Caregivers in Ndola District, Zambia.

Katentemuna Catherine Musonda^a, Mathew Nyashanu^b,
Wilbroad Mutale^c , Doreen Sitali^d, and Oliver Mweemba^e

^aHealth Promotion Officer Ministry of Health Zambia, Lusaka, Zambia; ^bPublic Health, Nottingham Trent University, Nottingham, UK; ^cSchool of Medicine Lusaka Zambia, University of Zambia, Lusaka, Zambia; ^dLecturer in Public Health – Health Promotion and Education, University of Zambia, Ridgeway Campus, Lusaka, Zambia; ^eDepartment of Public health, Ridgeway Campus, University of Zambia, Zambia;

ABSTRACT

In order to explore informal Home-based palliative caregivers' challenging experiences, this study gives an overview of the need of Home-based palliative caregivers in communities. Dialogs using In-depth interviews (IDIs) with twenty-five (25) purposively and conveniently selected respondents aged 18 years and over were conducted. They were not professional caregivers but volunteers from within the community attached to health facilities in Ndola. Discussions on global, Africa and Zambian' situations, and Ndola in particular were included. The findings, using thematic analysis, were lack of supporting resources, inadequate coordination, lack of training, undesirable working conditions and unreliable transport network. The study will facilitate formulation of guiding principles and policies for palliative care practices through recommendations based on results from this study to improve and sustain palliative care services.

KEYWORDS

Palliative care; informal Home-based palliative caregivers; end of life; quality of care

Overview

There is a general increase of people diagnosed with chronic illnesses which ultimately leads to terminal and potentially distressful situations and end-of-life periods at home. Due to poor funding many patients undergoing palliative care at home depend on family members, friends, neighbors and informal caregivers such as community home-based volunteers (Krug et al., 2018). There are more people undergoing palliative care at home in many low and middle-income countries due to underfunded and weak health

CONTACT Nyashanu Mathew  mathew.nyashanu@ntu.ac.uk  Public Health, Nottingham Trent University, Nottingham NG1 4FQ, UK.

© 2021 The Author(s). Published with license by Taylor & Francis Group, LLC.

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.

infrastructure. This has given rise to the high demand for informal home-based palliative care staffed by community-based volunteers which comes with its own challenges. The study employed an investigative qualitative approach to interview 25 informal Home-Based Palliative Caregivers (HBPCs).

Introduction

Globally, chronic illnesses which lead to terminal and distressful situations accounted for about 38,600,000 (1.0%) Human Immune-deficiency Virus (HIV) cases under the care of Home-Based Palliative Caregivers (HBPCs) (World Health Organization (WHO), 2008). By 2006, mortality rate of about 2,800,000 (7.3%) was reported. Similarly, the region of sub-Saharan Africa with Zambia included had many cancer cases which negatively affected the socio-economic wellbeing of individuals in developing nations (Downing, Powell, & Mwangi-Powell, 2010). The shortage of skilled manpower and medication in health institutions has made it difficult to manage patients with chronic conditions leaving the burden to the voluntary sector, friends and relatives in a home environment. This has led to the establishment of an informal HBP care as an alternative strategy to offer cost effective palliative service (WHO, 2008) In 2018, among the priority preference, Palliative home-based care scored 21–22% respectively (MacPherson et al., 2020). It is important to note that Home Based Palliative Caregiving (HBPC) is a daunting task which accounts for an estimated 50 million chronic cases under informal HBP caregivers dying each year with attention requiring holistic support, care and treatment. Some of the activities performed in HBPC include bathing, wound cleaning, toilet care, bladder care and continued psychological support (Cheong, Mohan, Warren, & Reidpath, 2019). In many circumstances such tasks require the services of highly qualified professionals.

The hours and burden of care vary for caregivers during acute and chronic treatment phases and at the end of life (Aoun et al., 2015). HBPC is characterized by long working hours in stressful conditions (Given, Given, & Sherwood, 2012). This burden of care in HBPC is what most health institutions leave in the hands of informal caregivers (untrained community-based volunteers) affiliated to clinics. This happens in most developing countries like Zambia. This has been exacerbated by rising numbers of chronic illnesses in people infected with HIV and the rising cases of complicated non-communicable diseases (NCDs) such as Hypertension, Diabetes and life-limiting illnesses such as Cancers (Hudson et al., 2015). The situation is also complicated by late presentation and diagnosis of HBPC patients due to weak health infrastructure in many developing countries. This also makes it difficult for the carers to take

decisions on some of the cases with regards to supporting them. The other thing is inadequate Home-based Palliative Care (HBPC) services due to resource constraints. These lead families/communities facing chronic and terminal illnesses to live in a lot of anguish.

HBPC is considered as an integral part of health and social care systems of long-term care given to individuals at home, who are not fully capable to long term self-care. The service is normally performed by nonprofessionals in this case who serve primarily as links between clients and other health care institutions (Ibid). Evidence shows that HBP caregivers make significant and unique contributions to community care outcomes underpinned by their unique relationship with patients, relatives and the community at large. This means that streamlining Palliative Care (PC) from technical health institutions may help in decongesting health facilities. Whilst this seems a solution for health institutions, it places a huge burden in the hands of HBP caregivers (Gysels et al., 2013). There is limited literature to back evidence of how informal HBP Caregivers handling chronic and terminal illnesses in Zambia operate. Palliative Care Alliance of Zambia, 2008 and African Palliative Care Association in their annual reports of 2013–14, discussed issues of professional caregivers only and not informal HBP Caregivers. This left a huge gap in knowledge which requires further tapping to enable integrating HBPC into the mainstream health system and eventually improve the health outcomes of the HBPC patients (WHO, 2008). In light of the above assertion this study was set to explore the challenges faced by informal home-based palliative caregivers.

Research setting

Ndola district is situated on the Copperbelt Province of Zambia and caters for a population of about 625,574. Health facilities under the district include Chipokota Mayamba and Chipulukusu health centers. The district has a population of over 100,000 people. The health centers were incorporated in an introduction to home based palliative care model which saw the introduction of the HBPC programme currently run by volunteers, friends and families of patients. The project was set under the auspices of the Tropical Health Education Trust (THET) funded by the Department for International Development (DFID) UK. It was a project extended from Uganda in a 3-year partnership to strengthen and integrate Palliative Care in Ndola.

Methodology

The study employed an explorative qualitative approach to seek answers to the challenges faced by the informal HBP Caregivers in a systematic way

without predetermining the findings (Dominici, Boncinelli, & Marone, 2019). This method is ideal to understand the problem being studied as opposed to offering conclusive solutions to the problem. The method values the lived experiences of the research participants as the final output of the study (Creswell & Poth, 2016). The idea behind this method is to obtain enhanced and divergent understanding of challenges in the HBPC process.

Recruitment and sample

The research team planned and worked together in close consultation with the Provincial and District Health Directors, as well as Nurses in charge at Ndola Health facilities to recruit the research participants for the study. This enabled them to identify and enroll participants who were operating under the district health facilities as volunteers in palliative care. Research participants were drawn from Chipokota Mayamba, Twapia, Chipulukusu and Chichetekelo communities using purposive sampling technique (Etikan, Musa, & Alkassim, 2016). One hundred and fifty (150) Informal Home Based Palliative Caregiver's names believed to be practicing PC were identified by the facility Nurse in charges with the help of Neighborhood Health committee executive members from their registers. Follow invitation letters to take party in the study only 25 caregivers expressed interest in taking party in the research study.

Inclusion and exclusion criteria

The informal HBP caregivers who took part in the study were all the community-based volunteers. The research participants age ranged from 18 to 65 years. They were all from Ndola district. 18 years was chosen as a cutoff point to circumvent the problems of consent as anyone under 18 years is regarded as a minor under Zambian legislation. All research participants should had worked as community-based volunteers and HBP Caregivers for more than 2 years. The two years thresh hold was chosen in order to recruit research participants who had experience in understanding the challenges in the field of palliative care under study.

Data collection instruments

Data collection was done using a pre-tested semi structured interview guide to ensure good quality data was collected. The interview guide was established based on the work from preceding literature of primary and secondary research studies. To test the appropriateness of the interview schedule, four research participants were interviewed. After the completion of the

Table 1. In-depth interview guide.

Research questions	Major thematic responses	Sub-thematic responses
1. What kind of resource support have you been receiving when caring for the people with chronic and terminal illnesses like cancer, HIV/AIDs, stroke etc. in your community?	<ul style="list-style-type: none"> • <i>There has been Lack of supporting resources</i> 	<ul style="list-style-type: none"> • <i>Scanty supplies</i>
2. How have you been working with other HBPCs?	<ul style="list-style-type: none"> • <i>There has been Inadequate coordination</i> 	<ul style="list-style-type: none"> • <i>Limited teamwork</i>
3. Explain some of the major problems that you have been facing in the process of caring for the chronically and terminally ill patients in your community?	<ul style="list-style-type: none"> • <i>Un-desirable working conditions.</i> • <i>Un-reliable transport network.</i> • <i>Lack of trainings</i> • <i>Inadequate coordination</i> 	<ul style="list-style-type: none"> • <i>Low motivation</i> • <i>Late referrals</i> • <i>knowledge and skill gaps</i> • <i>Limited teamwork</i>
4. What do you think could be done in order to improve informal HBPC in communities	<ul style="list-style-type: none"> • <i>Institute trainings</i> • <i>Improved working conditions</i> • <i>Improved transport network.</i> • <i>Improved coordination</i> 	<ul style="list-style-type: none"> • <i>Motivation</i> • <i>Timely referrals</i> • <i>Enhanced knowledge and skills.</i> • <i>Teamwork</i>

pilot interviews, the research participants were asked whether they felt that the interview schedule was suitable for the topic in question. None of the four research participants suggested any substantial changes to the initial interview schedule and it was therefore adopted for use in the research study. However, where appropriate, their comments were included to shape the final research interview schedule (Klietz et al., 2019) (Table 1).

Data analysis

All interview responses were recorded digitally after obtaining informed consent to capture verbal responses ahead of interviews by the researchers. Expanded Notes for nonverbal responses were taken by the research assistant during the interviews to compliment verbal responses. The transcribed data were coded and thematically analyzed shaping it into significant emerging themes. The analysis was guided by the four phases of The Silences Framework (TSF) (Serrant-Green, 2011). The four phases included the coding of the data into broad categories by the researchers in phase 1. During phase 2 of data analysis, the researchers took the categorized broad themes to the research participants for verification and confirmation as a true reflection of what they had said during the interviews. The research participants at this point had the opportunity to refute or confirm the constructed broad themes in line with their contribution at interview. At phase 3 of data analysis, the data from phase 2 were taken to a collective voice group for validation and verification. The collective voice group is a group of people who mirrored the research participants but did not take part in the research study. For example, this group was made up of HBP caregivers working in Ndola who did not take part in the study. At this point, the

user voice group validated and verified the data made up in phase 2. This was meant to critique the data using an associative critical eye. Finally, in phase 4 the researchers analyzed the data in line with the contributions made in each phase to form the final output of the research study. The code categories and final themes were supported by quotations from the research participants and revised by the investigators to enrich the power of the study.

Data validity and Reliability

The authors pursued an evaluation process to determine the quality of the study through the pre-testing the research instruments by conducting satisfactory in-depth interviews on a pilot sample. The strength, rationality and dependability of the data instruments were also tested by inquiring the views research participants on the data collection tools. The four phases of data analysis in The Silences Framework triangulated and validated the findings of the study.

Results

The study found that the challenges faced by informal HBP caregivers included Lack of supporting resources, Poor co-ordination, Lack of training, Undesirable working conditions and unreliable transport network see Table 2.

Lack of supporting resources

The researchers reported that HBPC operations were weak due to scanty supplies of logistics to meet most patient' needs. This was because kits containing medical and surgical materials (for example, gloves, antiseptics, strong analgesics, and other drugs) were rarely supplied. This affected good hygiene for patients. The caregivers further narrated that there was also shortage of food for the patients which affected their health outcomes. There were reports of patients becoming weak because of poor diet. There was also shortage of stationery making it difficult to maintain effective records for both the patients and organization.

... .. We do have material help from some well-wishers sometimes, not always. We receive various items to use, though not adequate because we do not determine the amount of donations, what to be donated and when. Sometimes we receive items we may not even need. So, donations cannot be reliable. A male HBP Caregiver

... .. it is very difficult to give comprehensive care to the patients we look after as caregivers in our community when all you have to do is "just chatting with them," no

Table 2. Themes and sub-categories.

Major Categories	Sub-categories and their open codes
Lack of supporting resources	Scanty supplies <ul style="list-style-type: none"> • Working kits for surgical & medical materials are scarce. • Food supplements for patient's nutrition are not available. • Stationary is mostly out of stock
Poor coordination	Limited teamwork <ul style="list-style-type: none"> • Disunity / HBPCs work in isolation • Family Caregivers not cooperative • Professional HBPCs absent
Lack of training and support	knowledge and skill gaps <ul style="list-style-type: none"> • Planning for intensive courses for HBPCs is not done • In-house orientations on new things does not happen. • Refresher courses are not done. • Technical support and supervision • IEC materials e.g. Posters, protocols & guidelines, • Performance Assessments feedback
Undesirable working conditions	Low Motivation <ul style="list-style-type: none"> • No office space/ Storage • Long working hours • Undefined job description (work-overload) • Cost burdens • No Rewards/recognition • Burnouts
Unreliable transport network	Late referrals <ul style="list-style-type: none"> • No transport money for booking taxis • Zam-bicycles broken down • Lack of airtime for communication • District ambulance prioritized for Maternity cases.

items to use, no food... ..at the same time we have got limited types of drugs especially Morphine for severe pain relief for instance. A female HBP Caregiver

...just the procedure itself to acquire morphine is something else because once a patient is in severe pain, you have to scout for a medical profession to prescribe and then look for transport money to go and collect the medication from Ndola Teaching Hospital where one has to be on long queues and answer to a lot of questions before being given the drugs. It is so stressful. A female HBP Caregiver

Poor coordination

The research participants reported disunity and poor coordination as one of the major challenges in the general operations of the informal HBPCs. They also reported limited teamwork. For example, during outreach visits, families and patients rarely cooperated with the informal HBPCs. They were deemed uneducated volunteers and not professionals with skills and vast knowledge. They reported that some families and clients desired Professional palliative caregivers from the local teaching hospital.

... ..It is necessary to combine efforts in this work but each one of us caregivers feel like we own patients in our care and because sometimes some caregivers have few uncritical patients who they manage with ease, they don't think of working together with others struggling with critical patients requiring turnings, lifting and other critical care packages. A spirit of selfishness; indeed, no unity amongst us caregivers because people want to work the way they want. A female HBP Caregiver

... .. I at one time found a patient locked up inside the house all by himself and I had to peep through the window to ask whether he had eaten or taken his TB drugs; I found this to be so demeaning to patients and could worsen their conditions due to stress and trauma. There is need for co-ordinated working to cover all patients. **A male HBP Caregiver**

... Underrating us as mere volunteers is the worst frustration in our job, family caregivers are too busy to be advised and taught the little that we know, they feel like we waste their time when we go their homes. They are the ones who contribute to poor conditions of these patients. **A female HBP Caregiver**

Lack of training and support

The research participants reported lack of trainings in caregiving. It was outlined as having contributed to knowledge and skills gaps in their practice. They reported that little attention was being given to planning for intensive courses for informal HBPCs by Health facility managers such that not even in-house orientations or refresher courses were being offered. The absence of technical support and supervision during patient visits made work difficult for informal HBPCs.

... .. No serious training has ever taken place apart from the first orientation workshop we had on palliative care. I can't even remember the date, and it has been long because ever since Ms Rona Mambo a retired nurse from Chichetekelo hospice took us in home-based care in the 90's went, everything came to a standstill. So whatever little she taught us, that is what we are still applying in our practice. New knowledge on palliative care is just acquired through asking questions time and again from nurses who even seem busy to explain and don't know much as well. **A male HBP Caregiver**

... .. No-one came back to offer us some refresher course or even just making a follow up to see how we have been working. They do not even know if we do the correct things or not. We have never worked in collaboration with the trainers and other Palliative Care experts from Ndola Teaching Hospital. I would also love to see support in terms of PC books, posters, magazines, tool kits, protocols and guidelines on how to care for the PC patients you know. **A female HBP Caregiver**

Undesirable working conditions

The research participants reported long working hours; undefined job description with work-overload in their workspace. They also reported incurring unreimbursed costs in trying to meet community demands during visits. They reported poor rewards/recognition for the voluntary work they were doing.

... .. For outreach visitations we spend long hours walking to far flanked areas like Mabunga and Roma (2-3 hours) where some patients live. We spend even more hours working depending on what works are required to be done out there on particular

patients. We normally just see few patients because we just don't go to look at patients' faces; we take time to also talk to relatives on many issues surrounding the patients. This is because these people also go through sad moments and suffer in mind so they need psychological support too. **A female HBP Caregiver**

... .. That is why I told you earlier on that most of the times I just have to sacrifice the little portions of food and a bit of money available for my household. Personally, I do go to sell at the market when not caregiving and I do get small loans from Cetzam and other money lending institutions, this is what helps me to raise I get a little from. **A female HBP Caregiver**

Unreliable transport network

The research participants reported that they walked long distances on foot to visit patients which was very exhausting and affected timely visits. They also reported poor communication challenges, leading to delays in referring patients. The district ambulance was assigned to maternity emergencies ignoring cases under PC as they were not considered a priority. The research participants reported that they were relying on bicycles for transport which at times were not working.

... .. In the past we used to have bicycle ambulances, but since they broke down, we just shoulder lift patients and start walking with them slowly to the health facilities. Sometimes for those who are unable to walk, we use wheelbarrows; if relatives have money they book taxis, if they don't have we ask from well-wishers for donations which is very hard because sometimes face negativity and we receive insults as answers. **A female HBP Caregiver**

... .. Walking long distances to areas like Mabungula and Roma is very exhaustive. By the time you reach there, it would be already late, and you could be very tired to do a good job in care and support. This why we need to be remembered with transport money or bicycles to use. **A male HBP Caregiver**

Discussion

The study has demonstrated that there are issues that positively or negatively shape Palliative Care. Among the issues are challenging experiences that have affected the delivery of HBP care to individuals toward the end of their lives.

Inadequate resources in patient care such as lack of food supplements may culminate into nutritional deficits leading to body wasting, anemia, diminished energy and organ failure (Khadka, 2019). Ideally certain medicines can cause ulceration of the bowels or the stomach if taken on an empty stomach; meaning adherence to medication could be affected as clients may fail to withstand the pain associated with drug intake, there by worsening conditions of patients with prolonged healing and severe

sicknesses (Lee, Yean, & Chao, 2016). If many clients or patients are in such situations, this translates into resource burdens and possibly an overburdened health care system. This could also escalate the hospital admission rates and diminish the bed capacity for emergency cases. Inadequate resources as alluded to earlier on leads to frustration of the Caregivers and subsequent poor care delivery (Shafer, Shafer, & Haley, 2019). The research participants reported lack of resources to support the informal HBP caregivers. In light of the above problems, there is need for effective communication between donors, ministry of health and informal HBP Caregivers to make sure that the potential suppliers of resources are privy to the nature of shortages being experienced by the informal HBP caregivers to avoid duplicating already available resources (Araújo, Silva, Bonfim, & Fernandes, 2010). Furthermore, it is important that informal HBP Caregivers are involved in carrying out the needs assessment of palliative patients to provide a primary understanding of the issues they experience everyday when working with individuals on palliative care. It is also imperative that the central Government of Zambia through the Ministry of Health (MOH) gives policy direction to recognize the legal existence and operations of informal HBP caregivers as a profession in the health care sector.

Coordinated working is very important in achieving the objectives of a team (Zhang, Azhar, Nadeem, & Khalfan, 2018). Lack of coordination can cause confusion and despondency in a team (Khadka, 2019). Coordinated working in health partnership requires a strategy cutting across the system and understood by all the partners involved (Bowen et al., 2019). In this study the research participants reported disunity and poor coordination as one of the major challenges in the general operations of the informal HBP caregivers. This made it very difficult for them to understand and handle certain serious conditions and quality End of Life for their clients. There is need for a strong, organized and coordinated leadership from the local ministry of health leadership through the local teaching hospital and health facilities to support the work of informal HBP caregivers. Through this organized structure the local teaching hospital in conjunction with other health facilities in the district can roll out localized training on coordination and teamworking with the informal HBP caregivers as recipients. Such organized training packages for informal HBP caregivers can result in coordinated working leading to achievement of positive health outcomes for people undergoing palliative care (Jack, Kirton, Birakurataki, & Merriman, 2012). It is also important that this coordinated working need to go beyond the work of informal HBP caregivers to also include different organizations that are involved with HBP care (Funk et al., 2010; Zerfu et al., 2012). This will enable timely referral of patients and addressing of imminent problems leading to positive outcomes for individuals on end-

of-life care while preventing burnouts and stressful conditions on the part of informal HBP caregivers. A culture of unity among informal HBP caregivers need to be fostered through organizational culture and mission statement. This may involve team building away days where the informal HBP caregivers will have an opportunity to build a working relationship with their colleagues and understand the importance of unity through harnessing the available skills and expertise when working as a team.

Training is an important facet of any progress workforce (Rubio et al., 2019). Through constant work-based training workers are able to improve the quality of work they do while demonstrating confidence and satisfaction from their work (Marques-Quinteiro, Vargas, Eifler, & Curral, 2019). Poor training at workplaces is associated with dissatisfaction, low confidence and high likelihood of accidents including mistakes at work (Han, Chen, Stemm, & Owen, 2019). The research participants in this study reported Lack of trainings in caregiving for individuals on end-of-life care. This made it difficult for the research participants to confidently discharge their work to the satisfaction of the individuals they cared for. In light of this assertion there is need for amalgamating the informal HBP caregivers with already established palliative care initiatives run by the ministry of health under the local teaching hospital and other health facilities. This will enable informal HBP caregivers to benefit from convectional palliative training convened and run by the local teaching hospital including local health facilities in Ndola. This will present the informal HBP caregivers with an opportunity to improve their skills by accessing up to date and validated palliative care courses (Saenko, Barsukova, Khokhlova, Ivashova, & Kenina, 2018). Family caregivers who were reportedly un-cooperative should also be given the opportunity to attend these trainings as a way of enlightening them on the importance of understanding palliative care and its importance to people undergoing it. Such a training can improve the working and coordination relationship of informal HBP caregivers with relatives of individuals undergoing palliative care. The improvement of this relationship has a direct impact on the health outcomes of the individuals on palliative care.

Facilitating favorable working conditions for caregivers is essential in fostering the provision of quality care (Alfano et al., 2019). Good working conditions are likely to motivate workers in doing their work with satisfaction and integrity (Mitonga-Monga, Flotman, & Moerane, 2019). The research participants reported lack of trainings in caregiving. It was outlined as having contributed to knowledge and skills gaps in their practice. They reported that little attention was being given to planning for intensive courses for informal HBPCs by Health facility managers such that not even in-house orientations or refresher courses were being offered. In light of

these assertions the central government need to put a policy that recognizes informal HBP caregivers and provide remunerations to offset unexpected costs that comes with volunteering (Panday, Bissell, Teijlingen, & Simkhada, 2019). More importantly a clear amalgamation of the informal HBP caregivers with already existing palliative programmes run by the ministry of health can enhance sharing of facilities and circumvent some of the shortage problems experienced by informal HBP caregivers in the process of discharging their duties.

Enhanced smooth and readily available transport logistics in making movements to and from places of care is very important (Van der Meer, 2008). Good transport network assists in easy delivery of resources and timely referrals of the terminally and chronically ill patients; this could also be a key motivating factor for caregivers' outreach activities. The research participants reported that they covered long distances walking on foot to areas of care. They also reported spending long periods walking to patients' homes which affected timely visits and referrals for progressive care. Furthermore, they reported that lack of transport facility and lack of money to book taxis hampered their timely execution of tasks critical to palliative care. It is therefore important to note that addressing transport challenges through financial support could enable clients to receive continuous quality enhanced care early enough. There is need for current transport support structures and systems in the ministry of health through the local teaching hospital and health facilities to support the informal HBP caregivers to timely attend their appointments with individuals under palliative care (Zerfu et al., 2012). There is also need for Government health institutions working with informal HBP caregivers to advocate for corporate social responsibility by engaging various partners like the faith groups, NGOs, and Private sectors for assistance in transport logistics to widen the scope of coverage and sustain informal HBPC programs.

Implications for practice

Palliative Care Services must be practiced based on integrated teamwork, responsiveness, advocacy, communication skills and consensus building. Informal HBP caregivers, therefore, need to be integrated with the wider informal palliative care structure manned by the ministry of health through its established health facilities. There is need for a multi-disciplinary approach to collectively respond to the needs and challenges that of informal HBP caregivers experience. This can be done through involving district nurses, social workers and health promotion practitioners who work in the community. This can help to connect the project to the mainstream palliative care and enhance collaboration with more experienced and financially stable palliative care organizations Furthermore, there is a strong need to

supplement the knowledge and skills base of informal HBP caregivers through palliative refresher courses and provision of reading materials for reference in their work. There is need for organizations managing informal HBP Caregivers to advocate for improved conditions in united agreement with the ministry of health and other salary and remuneration collective bargaining agencies leading to the legal recognition of the informal HBP caregivers as a profession. Findings of this study should be shared with all professionals who work in PC so as to raise awareness of the project affecting the services. The dissemination can be done through workshops and mini conferences with workers in different locations.

Limitations of the study

This research only considered informal HBP caregiver in Ndola. A more comprehensive research including other regions of Zambia may enhance comparison and generalization of the problems faced by informal HBP caregivers. The study utilized a qualitative approach with a small sample; therefore results should be viewed with caution. It does however, point to many needs identified by these caregivers. Research utilizing a mixed method in future may enhance exploration of issues discussed from different epistemological and ontological positions.

Conclusion

A need exists to integrate the informal HBP care into the formal palliative care supported by government through the ministry of health to ensure sustainability. More importantly there is an urgent need for training of informal HBP caregivers to enhance quality delivery of end-of-life care.

Acknowledgement

Our sincere thanks go to all informal HBP caregivers who participated in this study.

ORCID

Wilbrod Mutale  <http://orcid.org/0000-0002-6941-0193>

References

- Alfano, C. M., Leach, C. R., Smith, T. G., Miller, K. D., Alcaraz, K. I., Cannady, R. S., ... Brawley, O. W. (2019). Equitably improving outcomes for cancer survivors and supporting caregivers: A blueprint for care delivery, research, education, and policy. *CA: A Cancer Journal for Clinicians*, 69(1), 35–49.

- Aoun, S., Deas, K., Toye, C., Ewing, G., Grande, G., & Stajduhar, K. (2015). Supporting family caregivers to identify their own needs in end-of-life care: Qualitative findings from a stepped wedge cluster trial. *Palliative Medicine*, 29(6), 508–517. doi:10.1177/0269216314566061
- Araújo, I. M. D. A., Silva, R. M. D., Bonfim, I. M., & Fernandes, A. F. C. (2010). Nursing communication in nursing care to mastectomized women: A grounded theory study. *Revista Latino-Americana de Enfermagem*, 18(1), 54–60.
- Bowen, S., Botting, I., Graham, I. D., MacLeod, M., Moissac, D. d., Harlos, K., ... Knox, J. (2019). Experience of health leadership in partnering with university-based researchers in Canada—a call to “re-imagine” research. *International Journal of Health Policy and Management*, 8(12), 684–699.
- Cheong, W. L., Mohan, D., Warren, N., & Reidpath, D. D. (2019). Palliative care research in the Asia Pacific Region: A systematic review and bibliometric analysis of peer-reviewed publications. *Journal of Palliative Medicine*, 22(5), 545–552. doi:10.1089/jpm.2018.0447
- Creswell, J. W., & Poth, C. N. (2016). *Qualitative inquiry and research design: Choosing among five approaches*. Los Angeles: Sage publications.
- Dominici, A., Boncinelli, F., & Marone, E. (2019). Lifestyle entrepreneurs in winemaking: An exploratory qualitative analysis on the non-pecuniary benefits. *International Journal of Wine Business Research*, 31(3), 385–405. doi:10.1108/IJWBR-06-2018-0024
- Downing, J., Powell, R. A., & Mwangi-Powell, F. (2010). Home-based palliative care in sub-Saharan Africa. *Home Healthcare Nurse*, 28(5), 298–307. doi:10.1097/NHH.0b013e3181dbf2b6
- Etikan, I., Musa, S. A., & Alkassim, R. S. (2016). Comparison of convenience sampling and purposive sampling. *American Journal of Theoretical and Applied Statistics*, 5(1), 1–4. doi:10.11648/j.ajtas.20160501.11
- Funk, L., Stajduhar, K. I., Toye, C., Aoun, S., Grande, G. E., & Todd, C. J. (2010). Part 2: Home-based family caregiving at the end of life: A comprehensive review of published qualitative research (1998–2008). *Palliative Medicine*, 24(6), 594–607. doi:10.1177/0269216310371411
- Given, B. A., Given, C. W., & Sherwood, P. (2012). The challenge of quality cancer care for family caregivers. *Seminars in Oncology Nursing*, 28(4), 205–212. doi:10.1016/j.soncn.2012.09.002
- Gysels, M., Evans, C. J., Lewis, P., Speck, P., Benalia, H., Preston, N. J., ... Higginson, I. J. (2013). MORECare research methods guidance development: Recommendations for ethical issues in palliative and end-of-life care research. *Palliative Medicine*, 27(10), 908–917.
- Han, S., Chen, H., Stemn, E., & Owen, J. (2019). Interactions between organisational roles and environmental hazards: The case of safety in the Chinese coal industry. *Resources Policy*, 60, 36–46. doi:10.1016/j.resourpol.2018.11.021
- Hudson, P., Trauer, T., Kelly, B., O'Connor, M., Thomas, K., Zordan, R., & Summers, M. (2015). Reducing the psychological distress of family caregivers of home based palliative care patients: Longer term effects from a randomised controlled trial. *Psycho-oncology*, 24(1), 19–24. doi:10.1002/pon.3610
- Jack, B. A., Kirton, J. A., Birakurataki, J., & Merriman, A. (2012). The personal value of being a palliative care community volunteer worker in Uganda: A qualitative study. *Palliative Medicine*, 26(5), 753–759.
- Khadka, A. (2019). *Comparative study of nutritional status of rheumatic heart diseases patients before and after the surgery in dharan and nearby VDC'S* (Doctoral dissertation).

- Klietz, M., Rippena, L., Lange, F., Tulke, A., Paracka, L., Dressler, D., & Wegner, F. (2019). Validating the Parkinson's disease caregiver burden questionnaire (PDCB) in German caregivers of advanced Parkinson's disease patients. *International Psychogeriatrics*, 31(12), 1791–1800.
- Krug, K., Ballhausen, R. A., Bölter, R., Engeser, P., Wensing, M., Szecsenyi, J., & Peters-Klimm, F. (2018). Challenges in supporting lay carers of patients at the end of life: Results from focus group discussions with primary healthcare providers. *BMC Family Practice*, 19(1), 1–9. doi:10.1186/s12875-018-0816-4
- Lee, J. J., Yean, Y. F. & Chao – International journal of nursing studies. (2016). Elsevier Volume 56, April 2016, Pages 17–26. *International Journal of Nursing Studies*.
- MacPherson, N., Montague, T., Aylen, J., Martin, L., Gogovor, A., Baxter, S., & Nemis-White, J. (2020). Canada's evolving medicare: End-of-life care. *Journal of Palliative Care*, 36(3), 169. doi:10.1177/0825859720924169
- Marques-Quinteiro, P., Vargas, R., Eifler, N., & Cural, L. (2019). Employee adaptive performance and job satisfaction during organizational crisis: The role of self-leadership. *European Journal of Work and Organizational Psychology*, 28(1), 85–100. doi:10.1080/1359432X.2018.1551882
- Mitonga-Monga, J., Flotman, A. P., & Moerane, E. M. (2019). Influencing ethical leadership and job satisfaction through work ethics culture. *Journal of Contemporary Management*, 16(2), 673–694. doi:10.35683/jcm19048.52
- Panday, S., Bissell, P., Teijlingen, E. V., & Simkhada, P. (2019). Perceived barriers to accessing Female Community Health Volunteers' (FCHV) services among ethnic minority women in Nepal: A qualitative study. *PLoS One*, 14(6), e0217070. doi:10.1371/journal.pone.0217070
- Rubio, D. M., Hamm, M. E., Mayowski, C. A., Nouraie, S. M., Quarshie, A., Seto, T., ... Norman, M. K. (2019). Developing a training program to diversify the biomedical research workforce. *Academic medicine: Journal of the Association of American Medical Colleges*, 94(8), 1115. doi:10.1097/ACM.0000000000002654
- Saenko, L. A., Barsukova, T. I., Khokhlova, E. V., Ivashova, V. A., & Kenina, D. S. (2018). Team building as a tool to strengthen the company's position in the market. *International Journal of Engineering and Technology*, 7(4.38), 431–433.
- Serrant-Green, L. (2011). The sound of 'silence': A framework for researching sensitive issues or marginalised perspectives in health. *Journal of Research in Nursing*, 16(4), 347–360. doi:10.1177/1744987110387741
- Shafer, J. S., Shafer, P. R., & Haley, K. L. (2019). Caregivers navigating rehabilitative care for people with aphasia after stroke: a multi-lens perspective. *International Journal of Language & Communication Disorders*, 54(4), 634–644.
- Van der Meer, M. (2008). Liberalisation, privatisation and employment conditions—the evidence of public utilities, public transport and home care in the Netherlands. *Labour Market*, 149.
- World Health Organization, World Health Organization. Ageing, & Life Course Unit. (2008). *WHO global report on falls prevention in older age*. Geneva: World Health Organization.
- Zerfu, T. A., Yaya, Y., Dagne, S., Deribe, K., Ruiseñor-Escudero, H., & Biadgilign, S. (2012). Home and community based care program assessment for people living with HIV/AIDS in Arba Minch, Southern Ethiopia. *BMC Palliative Care*, 11(1), 8–8.
- Zhang, X., Azhar, S., Nadeem, A., & Khalfan, M. (2018). Using building information modelling to achieve lean principles by improving efficiency of work teams. *International Journal of Construction Management*, 18(4), 293–300. doi:10.1080/15623599.2017.1382083