

**LIVED EXPERIENCES OF COMMUNITY HOME-BASED
PALLIATIVE CAREGIVERS IN NDOLA**

By

Catherine Katentemuna Musonda

A dissertation submitted in partial fulfilment of the requirements for the degree of Master of
Public Health in health Promotion Education, Theory and Policy.

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DECLARATION

I, **Catherine Katentemuna Musonda** declare that this dissertation submitted to the University of Zambia, School of Public Health is in partial fulfillment of the award of a Masters' degree of Public Health (MPH), Health Promotion specialty, this exists from my personal effort and does not absolutely form or in part for another degree to this University or any other Institute of Higher Education.

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Signed (Principle Supervisor).....

Mrs Sitali Doreen

Date:.....

Signed (Dean of School).....

Prof. Charles Michelo
School of Public Health

Date:.....

CERTIFICATE OF APPROVAL

This dissertation by **Catherine Katentemuna Musonda** is approved as a partial fulfillment for the requirements for the award of a Masters' degree in Public Health (MPH), Health Promotion specialty by the University of Zambia, School of Public Health, Ridgeway Campus, and Lusaka.

Examiner: 1 Dr. Zulu Joseph Signature..... Date.....

Examiner: 2 Mrs Chisala Meki Signature..... Date.....

Examiner: 3 Ms Kombe Maureen Signature..... Date.....

Name: Mrs Sitali Doreen Signature..... Date.....

Head of Department-Health Promotion, Education, Theory and Policy

ABSTRACT

Palliative care in Zambia began in the 1990's due to rising numbers of chronic illnesses of people infected with HIV and rising Non-communicable diseases such as Cancers at 60% in 85% of the Lower Medium Income Countries (WHO, 2014). The study was done in Ndola City, the Copperbelt provincial headquarter of Zambia catering for a population of about 400,000 people. The main objective of the study was to investigate lived experiences of Home-Based Palliative Caregivers of Ndola; in resource support services, psychological and opportunity gaining experiences, as well as challenging experiences. Home Based Palliative Care services remain inevitable under caregivers' hands with no formal training but there is scarcity of information about their operations in Zambia and yet terminally and chronically ill patient's demands on them remain very high.

A phenomenological study in qualitative research was conducted with in-depth interviews on twelve purposively selected respondents done. An interview guide, a digital recorder for responses and note taking to take care of other observations from non-verbal responses was used. Thematic analysis of manually created themes were arrived at during findings after exploring the lived experiences of caregivers and this method acted to provide a means to uncover deep understanding of the caregivers' experience perspectives formulated patterns.

Findings of negative experiences revealed: lack of team work, limited resource supplies such as inadequate Home Based Palliative Care kits comprising medical and surgical logistics; lack of food supplements to boost nutrition and many more limitations. Caregivers' duties too were associated with: work over- load, long working hours and cost burdens. In addition to career development was lack of the following: training, refresher courses, technical support supervision and standard guidelines. Whilst positive experiences reported were: hope for employment; feeling respected and highly regarded in their community bringing dignity, sense of self-worth, self-esteem; and self-actualization associated to impacting decisions made on people's health. This study therefore contributes to growth of research on determinants of health, a basis for further research by students, academicians; researchers to bridge knowledge gaps and provide evidence to inform policy in integrating caregivers' issues in a wider health care system and address health inequalities. The exploration of these experiences have put together logical evidence to inform policy; enable appreciating the roles of Palliative Caregivers in the general public domain and help integrate this in a wider health care system to provide for further research by students, academicians, researchers and policy makers.

DEDICATION

This study is dedicated to my beloved husband Bornface Musholomwe Makumba, my dearest mother Dorothy Mwila Musonda, my late father John F. Musonda and my entire family for understanding and supporting me during my heavy absence from home and denying them my time to care for all of them for longer periods whilst in school. To my sons Bornface Makumba Jr and Chinyimba Makumba thanks for the endless love you showered me with in times of stress and continuous computer guidance. My daughters: Mwila Makumba and Milan Nachinga; thank you for being there for me in every corner of our home to cushion my absence. Not forgetting my only young sister Mrs. Florence Musonda Nkonde and her husband Mr. B. Nkonde for their hospitality in their home and brother Webby Mumba Ngoma for motivating me greatly. I appreciate all of you.

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LIST OF ILLUSTRATIONS

Care givers: People who provide care and support to clients; they can be community volunteers or family members and are not usually paid for services rendered but can receive rewards (Hall & Philips, 2017).

Clients: People who seek integrated formal and informal services from their community and care organizations (Hall & Philips, 2017)

Non-Communicable Diseases: diseases which cannot be spread from one person to another directly but have devastating health outcomes causing complications like disabilities (Pramming, 2007).

Opportunistic infections (OIs): conditions occurring in clients with weakened immunity as a result of HIV, such as TB, pneumonia, fungal infections, skin cancers and many more conditions (Holmes & Kaplan, 2009).

Palliative Care: Specialized care focussing on increasing comfort through relief of pain, prevention and treatment of distressing symptoms including stress caused by serious illnesses (WHO, 2014).

Home-Based Care: Care that is not institutionalised but is given at home by community care givers who may or may not have undergone some basic orientation (Butts & Smart, 2017).

Home-Based-Palliative Care: un-institutionalized specialized care focussing on increasing comfort through relief of pain, prevention and treatment of distressing symptoms including stress caused by serious illness given by trained palliative caregivers (Bronskill etal', 2017).

Lived Experiences: philosophical knowledge from observations acquired through senses and not abstract reasoning prior to or when in active involvement or exposure in activities/events over a period of time that leads to an increase in knowledge or skill (Grover, 2017).

LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
APCA	African Palliative Care Association
ART	Antiretroviral Treatment
ARVs	Antiretroviral Drugs
CBO	Community Based Organization
CHW	Community Health Worker
EoL	End of Life
HBC	Home Based Care
HBPC	Home Based Palliative Care
HIV	Human Immune-deficiency Virus
MOH	Ministry Of Health
NCDs	Non Communicable Diseases
NGO	Non-Governmental Organization
WHO	World Health Organization
PCAZ	Palliative Care alliance of Zambia
PC	Palliative Care
SES	Social Economic Status
THET	Tropical Health Education Trust
WHO	World Health Organization

CHAPTER ONE

INTRODUCTION

1.1 Background

According to the World Health Organization (WHO), Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of distressing symptoms by means of early identification, perfect assessment and treatment of pain and other problems (Graham & Clark, 2008)

From 19th century roots, palliative care developed in the later part of the 20th century as a community undertaking and medical specialty. Dr Cicely Saunders according to Graham & Clark, (2008) played a significant role towards revolutionizing its improvement; her vision for improving the care of the dying incorporated the physical, psychological, social and spiritual domains. This evolved into the discipline of palliative care, which applied holistic principles to the care of those earlier in their disease path and in different settings, such as hospitals and the community (Ibid)

Thus known as continuum of care that can be carried out in the hospital, hospice or at home; in this study, the interest is in discussing Home-Based Palliative Care (HBPC) with regard to caregivers' experiences. This is considered as an integral part of health and social systems of long term care given to individuals at home, who are not fully capable to long term self-care (Sabate, 2003).

Palliative care (PC) in Zambia, began when the health care system in the 1990's, became overwhelmed with rising numbers of chronic illnesses of people infected with HIV and the rising cases of complicated Non-communicable diseases (NCDs) such as strokes from Hypertension, Diabetes and life-limiting illnesses such as Cancers. For instance, in one of the clinics in Ndola, the prevalence of hypertension moved from position 10 in 2012 to 7 in 2013, and in 2014 it moved up to top 5 in the list (Mackuline, 2015).

Hence, the strategies of streamlining care from institutional based to home-based palliative Caregivers (HBPC) in communities. The challenge of work overload, shortage of skilled manpower faced by health institutions and scarce resources for managing chronically ill patients requiring long hospitalization periods led to the existence of these strategies (Mackuline, 2015).

HBP caregivers in this case have been found to be an alternative strategy to offering cost effective than costly institutional care as stated by World Health Organization (WHO); averaging cost for medications per patient-year for palliative care estimated to be approximately US\$ 19. An analysis in both Sub-Saharan Africa and South East Asia of the cost of eight home-based care programs found that community-initiated care was both more effective and less costly with six months of care averaging US\$ 26 (World Bank, 1997).

Evidence showed that HBP caregivers made substantial distinctive contributions to community care outcomes underpinned by their unique relationship with patients, relatives and the community (Hill et al, 2014). This means that streamlining Palliative Care (PC) from technical health institutions helps in decongesting health facilities, though it has placed a huge task in the hands of Home Based Palliative (HBP) caregivers.

Globally, in 2006 this task accounted for about 38,600,000 (1.0 %) HIV cases are under the care of HBP caregivers, with mortality rate of about 2,800,000 (7.3%). Similarly, in sub-Saharan Africa with Zambia inclusive, have more than 50 million chronic cases under HBP caregivers dying each year (UNAIDS, 2012).

HBP caregivers are non-professionals serving primarily as links between clients, health care institutions and other service providers, who offer free volunteer labor in different communities (Duncan & Mitchell, 2004). They offer PC to patients with life-limiting illnesses to improve their quality of life and quality End of Life (EoL). The nature of PC given varies from client to client; meaning different patients with different chronic conditions have different needs leading to their diverse experiences known as social constructs of conscious thoughts of conditions, challenges, situations or contexts revolutionizing the phenomena (Ibid).

As these HBP caregivers continue to perform activities aimed at restoring good health, prolonging life and offering quality End of Life (EoL) to chronically ill clients in the community, primary health care is performed where health promotion (HP) is implemented and enhanced. This is because the Action Area “Strengthen Community Action” under the Focus Area of Public Health, “Community engagement and participation” to improve the health of the populations is at play as outlined in the Ottawa Charter conceptual strategies (World Health Organization, 1986).

The process of PC for caregivers is characterized by both negative and positive encounters; where positive encounters account for potential opportunities such as: attending some orientation meetings or workshops to gain understanding of the PC programs; rapport creation between clients and caregivers due to mutual trust, respect and co-operation enhances caregivers being recognized as important people in the communities they serve. This develops confidence in them; the caregivers then enjoy a sense of ownership of the program, and this builds on their self-esteem (Duncan & Mitchell, 2004). Some small incentive remunerations are also possible with involvement of stakeholders in numerous PC community funded programs during orientation workshops (Ibid).

Additionally, negative encounters for HBP caregivers characterized by challenges and gaps such as lack of material and immaterial resources required in achieving optimal care can occur. For example, lacking material resources of supplies like stationary, transport money, umbrellas, gloves and disinfectants; lacking immaterial resources of things like technical knowledge, skills, supports at both individual/organizational levels; psychological burnout; destruction of household economies; community stigma and rejection which result in negative experiences (Campbell & Foul, 2004).

The biggest problem is that, HBP caregivers have no formal training like Nurses in caring for the sick and worse still handling complicated illnesses like cancers and care of the terminally ill who are bedridden and have no care from their extended families; where children are found bearing the burden of care in many instances.

1.2 Statement of the problem

This study was pursued to investigate the experiences of HBP caregivers because it was evident that they had no formal training in delivering health care services and it was not so clear as to how they had been operating without skilled knowledge. Since literature available contained little information about caregivers, it was found necessary to investigate caregivers experiences during caregiving of chronically ill patient's demands which required a lot of expertise; particularly following infection prevention guidelines, managing side effects of strong drugs like morphine administered for distressing pain and other health problems that come along with illness.

WHO 2011, reports of disease burdens in HIV/AIDs and the continued rise in cases of cancer and other chronic NCDs stood at 60% in 85% of the Lower Medium Income Countries (LMICs). WHO 2014, then accounted for 23% deaths from chronic/life threatening NCDs in

Zambia alone, a problem rendering HBPC services to have remained inevitable with the presence of home-based palliative caregivers which proved to be very essential in spearheading community based activities. Despite their presence in this regard, their experiences during the processes of care had not been highlighted (Gysels et al, 2011).

Palliative Care Alliance of Zambia (PCAZ) and African Palliative Care Association (APCA) also outlined seemingly very good objectives in the annual report for 2013-14 for PC programs, but the problem was that these objectives never addressed caregivers' welfare issues such as resource availability. On the overall, there has been scarcity of information regarding personal experiences of HBP caregivers in Zambia

1.3 Aim

To investigate lived experiences of Home-based palliative caregivers in Ndola

1.4 Specific objectives

1. To describe resource support services for HBP caregivers in Ndola.
2. To explore personal psychological experiences of HBP caregivers in Ndola.
3. To determine the opportunities HBP caregivers in Ndola realize from HBPC practice.
4. To establish the challenges HBP caregivers encounter during caregiving processes in Ndola.

1.5 Research Question

What are the experiences of HBP caregivers in Ndola?

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter presents literature from different views and approaches concerning different roles of caregivers in palliative care; their experiences as regards resource allocation, psychological experiences, and opportunities experienced during the Palliative Care (PC) processes and programs, as well as the challenges they encounter during caregiving.

It is important to know that the well-being of patients with progressive cancer, together with rising existence of terminal illnesses in populations, is primary to the need for PC. In view of the unending requirement for discomfort and pain management in PC units, a small number of caring facilities are capable of offering long-stay admission for those whose symptoms have stabilized and do not need specialist PC services, leading to Home-Based Palliative Care (HBPC) being an alternative approach with reduced costs (Dumanovsky, 2016)

Graph 1: Prevalence of Palliative Care (Connor, 2017), How We Work: Trends and Insights in Hospital Palliative Care.

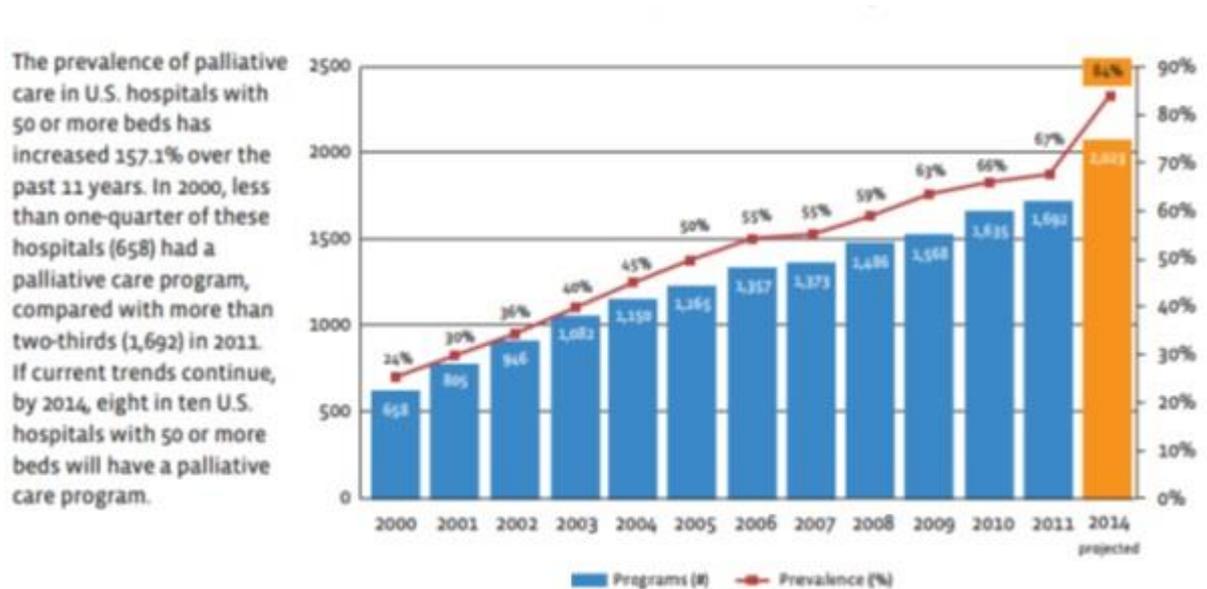


Figure 1: Prevalence of palliative care (2000-2011) in US. Hospitals with 50 or more beds

The above graphical literature indicates increases in the need for HBPC services because there is overwhelming bed capacity of admissions standing at 61% in the US alone which defines the importance of HBP caregivers for those discharged on the palliative care package. If in the developed nation trends of this service shown are so high by definition of 61% bed

capacity of chronic and terminal illnesses requiring Home-based Palliative caregivers' service when discharged, it is therefore prudent to explore caregivers' experiences in places like Zambia of the Lower Developed Countries which could be in worse situations, hence the study of caregivers in Ndola whose roles could equally be overwhelming.

2.2 The roles of Caregivers

A fundamental part of the role of palliative-care givers encompasses operating with patients and their families/carers when the care pathway shifts from End of Life care to supporting patients to cope with their chronic diseases, within extreme scarcity of resources and isolation. They also connect patients to formal health systems like hospitals and clinics when in need of continuum care for other services which they are unable to provide. They assist, monitor treatment and adherence provision through direct palliative and psychosocial care to HIV positive people, Cancer patients, other NCDs (Huariou commission, 2011).

Their family members receive psycho-social support too, which facilitates these patients to even live longer now than then. In the quest for extra multifaceted and all-inclusive support to manage life-limiting/chronic diseases in communities where stigma and discrimination remain prominent, caregivers now provide psychosocial counseling and HIV testing support services, nutrition assistance, and legal services. This reduces stigma, increases social acceptance through counseling and teaching prevention, sustaining good quality of life and promote socio-economic development (Ibid).

These are crucial roles which the caregivers facilitate, hence the importance of this study to understand the experiences the caregivers in Ndola have had during these processes of all these overwhelming caregiving roles.

2.3.0. Resource support to caregivers

To effectively sustain the stated roles of caregivers and afford Home-based care services to clients successfully, caregivers need certain resources. These resources can be generally categorized into the following: Money; Manpower or the people needed to assist; Materials or the goods, services and financial support; Moments or minutes (the time required); and technical support (Acker, 2007).

2.3.1 Money resource to strengthen caregiving

Money to both caregivers and patients is a significant means in the provision of Home-based palliative care. Ailments like AIDS and cancer are long, costly and incapacitating sicknesses

which require those caring for the sick to access such for effecting referrals in terms of booking taxis as well as taking patients for continuum of care like paying for X-ray or scan service. Unavailability of money resource in the long run renders the affected (family and caregivers) and infected incapable of buying goods such as food, clothing, drugs and other materials. They may also need to pay for health, legal and other services like transport (Acker, 2007). Lastly information package on what they ought to do in all areas of Palliative Caregiving is also an important technical support resource they need.

A study involving 10 Home Based Palliative Care service providers, purposively selected was reviewed. The objective was to assess the status, inadequacies and prospects of care and support services caregivers receive to provide care to people with cancer and those living with HIV/AIDS in the town of Arba Minch, Ethiopia, and surrounding areas. The study revealed caregiver's experiences of support services in money terms (Zerfu & Yaya, 2012). Information was gathered using a pre-tested structured interview questionnaire and in-depth interview guideline. Results revealed inadequate financial support from both external and internal stakeholders to help caregivers in proper service delivery especially enhancement of referrals between different care providers. They also cited this as a drawback in care and support to their efforts as care and support services provided to PLWHAs in the study area are by far lower in terms of coverage and quantity as money to cater for transport costs is a challenge (Ibid).

Zambian caregivers' also need to walk distances to offer caring services in communities which sometimes call for 24 hours care, and making such movements requires money. Milliah Mhlanga, a 62 year old Home based caregiver, who lives in Desai compound in Lusaka, Zambia who belongs to the **Zambia Homeless and Poor Peoples Federation (ZHPPF)** narrates that she has been a Home based caregiver for eight years now and offers her help voluntarily to people in her area especially those that had been discharged from hospital but were not yet strong enough to do household chores, and she says she goes to their homes to help regardless of the distances involved (Home-Based Care Alliance, 2012). In view of this however, there is scanty information to adequately state how the caregivers in Zambia manage in rendering home-based palliative care services which require funds.

2.3.2. Manpower to support caregivers' capacity to provide Home-Based Palliative Care
Work-overload is one potential challenge that HBPCs are likely to encounter because of the rising NCDs alluded to in the background information. When the Hospital Facilities

discharge patients back into the community, HBPC services, take over to supplement efforts of caring for the chronically sick adequately. Though diverse manpower is another essential resource required, it seems difficult to be readily available to supplement Home-Based Care services and this renders caregiving overburdened with work overload. Caregiving needs to be a collaborative partnership in providing care and support to clients and the affected, the reason why Health workers at all levels; Family members, relatives and friends; Community leaders; Spiritual, political, and administrative leaders should be involved as extra manpower to HBP caregiving (Home-Based Care Alliance, 2012).

The other reason for manpower supplementation is the issue of specialization, its usefulness in continuum of care. This is because different service providers can provide a variety of services and it is important to understand what service each person can provide so that clients or patients can be referred appropriately (Cassel et al, 2011). In South Africa, 105 systematically reviewed articles under interviews and descriptive thematic analysis discussion were reviewed. This was centered on care givers' activities in Home based palliative care services which cover a wide range of needy areas including family participation. Key results of the peer review were that no proper definition was done in relation with issues to do with supporting human resource to caregivers. To this effect, findings suggest there is need for knowledge building as regards other human resource involvement to care giving for patients, where family members are urged to work together with the volunteers and take a leading role in the care (Funk et al, 2010).

2.3.3. Materials for caregivers to use on chronically and terminally patients

People Living with HIV/AIDS (PLWHA), cancer and other life limiting illnesses require significant care and support from the palliative caregivers using various materials. Materials range from items like bandages to use on patients with wounds; gloves and disinfectants for infection prevention during caregiving like bathing patients, HIV testing, cleaning and washing linen and etc; however, most care needs are unmet because most of the HBP caregivers who offer them the care lack adequate materials to use (Campbell & Foulis, 2004). Many illnesses that require home-based care tend to render the affected persons incapable of meeting even the most basic material needs of everyday life like hand soap, protective clothing, stationary and many more logistics. For instance a PLWHA may become too weak to fetch water or firewood, or run errands and do shopping. Food production may be affected due to frequent sickness from opportunistic infections. Thus, the patients depend on caregivers for such material resources required to assist in smooth caregiving. These

materials range in the forms of food, cooking fuel (like firewood), water, or money for drugs and other purposes (Acker, 2007).

These materials may not be readily available for caregivers to access unless there is willingness within communities by individuals, families or organizations such as some non-governmental organization to donate some of the materials or money to procure them. Some of the materials can also be obtained from the hospital such as essential drugs, ARVs and drugs for opportunistic infections at the primary health care level; Detergents, antiseptic soaps and also advocacy services; Home care kits with basic items to use. This is to strengthen the capacity of care providers to properly manage people with chronic and other life-limiting illnesses like cancers (Acker, 2007).

2.3.4. Time resource for Home-Based Palliative caregivers to implement caregiving

Moments or time for caregiving are very important for taking care of patients with long-term illnesses and this could be intense, time consuming and an emotionally draining experience. Caregivers may experience little time to attend to their important aspects of everyday life, like working on the farm, going to work, school, or running errands. This is because of the continuous demands to care for patients and clients which can be very stressful. Yet, time is one of the most essential resources known to man to be able to achieve such tasks, because it is an essential commodity (Frank, 2008).

Some trained caregivers in South Africa in an interpretive phenomenological study, established some difficulty with negotiating times when they experienced problems in both their personal and work lives. Participants found the mixture of work and personal problems as generating additional and endless problems. Caregivers' ability to stabilize their personal lives and their caregiving roles is an obstacle to time balancing (Frank, 2008). This results in competing priorities and affects caregivers too, because these are people who have other social roles and tasks to fulfill in their ordinary lives taking into consideration they have families to fend for. Therefore dividing time to look at what to do first becomes a challenge (Dambisya & Matinhure, 2012).

2.3.5. Information package for Home-Based Palliative Caregivers to use

Technical support is scientific assistance; where for instance information dissemination to caregivers is done; in-house trainings and other activities from professionals are very important to enhance adequate/quality of care to the community. Wherever and whenever palliative care is provided, factors to be assessed include affordability and the presence of health information for community care and support services such as guidelines and training for palliative caregivers. This is because when patients choose to be at home, caregivers can be trained by professional health workers like Nurses and Doctors to effectively provide professional information to enhance support in giving correctly prescribed medications and apply other physical and psychological care services properly as may be needed (WHO, 2002).

Improved communication through professional advice, supervision and acquisition of adequate health information from provided guidelines, represents a potentially effective method of increasing caregivers' confidence in their ability to undertake practical aspects of home-based care. It is important that nurses and other health providers may better assist home-based palliative caregivers by providing updated information during community supervisory visits and skills-training regularly necessary to facilitate this. This may necessitate the involvement of carers in the design and testing of new educational interventions (WHO, 2002).

Caregivers' accessibility to information is in context with enlightening them in symptom management, proper practice during hands on with some home-based basic procedures like wound dressing; proper referral of clients for continuum care to other service providers; counseling and testing; observing universal precautions of infection prevention and so forth. This could benefit patient and caregivers' desires in relation to addressing distressing symptoms in advanced disease and improve quality of health (Hudson, et al, 2008).

Literature has shown that family/PC volunteer caregivers in palliative home care ought to have basic knowledge for enhanced communication with health professionals to have their needs for psychosocial support and information met. According to this perspective, caregivers in PC ought to be knowledgeable and get sustenance to this call from health professionals if they must improve in the quality of care to offer (Holm et al, 2015).

The way training on the provision of palliative care should be incorporated into the curriculum for all professional health care providers, guidelines for home care services which incorporate basic management of palliative care by family members and HBPC volunteers should also be done in the same way by being included in their training courses and orientations organized and provided by professional health care workers at the community level. In all of the above, indicative care and pain control using the full analgesic order should be incorporated (Holm et al, 2015).

It is believed that “As a priority, informal carers need equitable access to high quality, flexible information services that can be used to be able to respond to individual needs and circumstances. Hence a number of interventions and services have been developed to support informal carers. However, concerns exist regarding the availability, accessibility and equity to this palliative care provision information and the challenges this poses to caregiver autonomy. Tailored, responsive support may be needed because each family and caregiving situation is unique” (Dionne et al, 2016).

2.4 Psychological experiences

2.4.0. Burdening experiences

The Burdens of Caregiving can be emotionally challenging at times and in view of fulfilling the caregiver’s roles, they encounter what is known as "caregiver burden" comprising physical, emotional, financial, and social problems associated with caregiving. Examples include forced changes in household routines, missed days of work, family frictions, reduced social contacts, loss of income, and/or reduced energy (O’Neill, et al, 1999).

Subjective burden assesses the caregiver's views and responses to caregiving demands. Caregivers with high levels of personal burden may report "feeling trapped," "feeling nervous or depressed about their relationship with the care recipient," or "resenting caregiving tasks" even when their objective burden is relatively low (O’Neill, et al, 1999). Caregiving commonly arises as an unpredicted role, one for which people are neither socialized nor prepared for. To take up this new role, caregivers need to re-organize foregoing role commitments as well as social undertakings. Interactive pressures might increase as the caregiver and care recipient endeavor to resolve issues of independence and reciprocity inside the context of a progressively more unbalanced relationship. This is the reason why assessments of what caregivers go through when caring for people living with NCDs is such an important thing to do as it can involve mental stress (Ibid).

A study was conducted in two districts located in the middle part of Ghana, pursued using qualitative approach with In-Depth Interviews and Focus Group Discussions conducted among caregiver's seventy five (75) respondents in the Kintampo Health and Demographic Surveillance Systems. Data gathered from caregivers' encounters revealed that: Caregivers underwent burdens of financial, social exclusion. It also revealed that levels of the caregivers' psychological adjustment in cancer caregiving, stress management for providing care resulted into both negative and positive affects (Kim & Baker, 2006).

2.4.1. Caregiver's stressful experiences

When caring for the sick certain bad encounters like being scalded by community members or failing to fulfill caring activities because of inadequate resources could precipitate emotional stress. Stress has been implicated in a wide variety of psychological and physical problems ranging from anxiety states especially when the demands made on caregivers become greater than their abilities can manage to cope. It is not easy to control and reduce such emotional stresses of caregivers. This becomes a burden on health care and support programs (Porter, 1999).

In South Africa, some volunteers from a HBP care organization were exposed to a study which explored challenging experiences that affect caregivers using an interpretative, phenomenological paradigm. It involved 11 participants aged between 20 and 65 years of age who lived in the same community and worked for different periods as caregivers in Home based palliative care work. Data was obtained through semi-structured interviews of caregiver's experiences and perceptions. Positive and negative elements of their emotional impact brought out responses of emotional stress as their biggest challenge, attributed to work overload (Blanche & Kelly, 1999).

To evaluate a one-to-one psycho-educational strategy aimed at reducing psychological distress of caregivers caring for patients with advanced cancer in receipt of Home Based Palliative Caregiving services, a randomized controlled trial comparing two versions of the delivery of the intervention (one face-to-face home visit plus telephone calls versus two visits) plus standard care to a control group (standard care only) across four sites in Australia was done (Hudson et al, 2015). This author reported the results as follows:

Enrolment in a single visit had fifty seven (57) participants, the two visits condition was to have ninety three (93) participants, and the control had 148. It was reported that there were non-significant changes in distress between times one (1) (baseline) and two (2) (1-week

post-intervention) but significant gains in competence and preparedness. There was significantly less worsening in distress between times 1 and 3 in the one visit intervention group than in the control group; however, no significant difference was found between the two visit intervention and the control group (Hudson et al, 2015). These results have been stable in line with interventions, besides sustenance of prevailing proof representing fairly little psycho-educational interventions which support family caregivers who are supporting patients. The sustained help may also apply during the bereavement periods.

2.4.2. Caregiver's coping strategies

Coping strategies for Home Based Palliative caregivers are adaptive plans or mechanisms which require self-motivation. Unsuccessful coping approaches could intensify the undesirable emotional effect on individuals, even though in effect coping can be emotionally protective. Managing schemes are defensive when they put up with helpful emotions. Hence helping as a reserve contrary to undesirable influences; they can in turn replace coping mechanisms (Pierce et al, 2007).

Thoughtful subjective significance caregivers attribute to both positive and negative experiences provides intuition into the process of caregiving and the influences on caregivers' experiences from a phenomenological perspective. This kind of consideration to caregivers' positive experiences can foster these experiences and reinforce strategies that promote and prevent negative experiences, thus increasing the caregiver's coping ability (Pierce et al, 2007). Exploring further in what way coping worked as a major constituent meant for trained caregivers and professional nurses in a palliative care setting, an interpretative, phenomenological method to discover this was done in South Africa (Braun & Clarke, 2006). Results comprised seven themes that offered understanding keen on how participants observed the character of coping and the diverse support mechanisms accessible to them. The themes proved how participants' ability or inability to achieve workload with day-to-day challenges went on.

2.5 Opportunity experiences

Employment opportunities for Home Based Palliative Caregivers are possible from the caregiving process because caregivers' roles in executing Palliative Care have acquired them remarkable amount of expertise in caring for people with HIV/AIDS, cancer and other chronic illnesses in underprivileged and isolated communities such that this expertise makes them become potential for employment when chances allow.

Findings from a study in Australia whose sample, consisted of one hundred and twenty five (125) family caregivers and took place in three specialist PC units and one hematology unit intended to describe states of minds on reward amongst family caregivers in the course of ongoing Palliative Caregiving and also to compare their experiences of rewards in relation to sex and age (Jack and Kirton, 2012). Positive affects and rewards were expressed in relation to employment opportunities that came along with providing care for cancer survivors. These findings played an important role in developing targeted programs to lessen psychological suffering of cancer caregivers with numerous responsibilities then. This helped them in identifying their caregiving experiences as meaningful (Braun & Clarke, 2006).

Rewards in terms of being appreciated and motivated as caregivers are different forms of opportunities; where Palliative caregivers seem to experience happiness. Participants answered a questionnaire including demographic background questions rated as Rewards of Caregiving Scale (RCS). Descriptive statistics were employed to describe characteristics of the participants and the level of rewards where a Mann-Whitney U test was used to compare differences between groups of different sexes and ages (Jack & Kirton, 2012).

Results revealed that Palliative caregivers reported general high levels of reward and supreme sources of rewards involved feelings of being useful to patients, followed by giving something to patients that brought them joy and just being there for the patients and meeting their needs raises their self-esteem. This was associated to personal growth, self-satisfaction, and personal meaning attributed to positive feelings of caregivers during ongoing palliative care. Regardless of their unique and stressful situation in some instances, a study among caregivers who worked in AIDS service organizations in Ontario, Canada revealed caregiver's inherent enriched self-worth and health, and self-actualization experiences (Jack & Kirton, 2012). Furthermore, social status of the caregivers in their communities was said to be uplifted because of the recognition they had obtained in the community for doing community work (Ibid).

2.6 Challenging experiences for the Home Based Palliative Caregivers

The caregivers' roles are so demanding on the market, especially now when the patients requiring their services are on the rise, evidenced by increases in the figures of Non-Communicable Diseases alluded to in the background chapter of this study. Sub-Saharan Africa's caregivers review that PC system is marred with lack of knowledge, lack of skills, lack of support both at individual/organizational levels; physical and psychological burnout

due to work-overload; destruction of household economies; community stigma and rejection (Campbell & Foulis, 2004). Therefore it requires serious stakeholder involvement and support for it to be sustainable. There is absolute need for these groups of care givers to continue executing these caring functions as the sick population continues to grow. When there is work overload, no motivation or support, the PC program may suffer serious burnouts (Ibid).

Stakeholder involvement and knowledge building through trainings; logistical support, inclusiveness in planning; and urge to work together with families and take a leading role in the care is therefore necessary if burnouts have to be avoided and sustain the program. In Uganda; the capacity of family with other caregivers to provide care repeatedly becomes inhibited by a conflicting understanding of task shifting between different stakeholders. This is because of poor communication between caregivers and health care professionals. It is the biggest gap in caregiver's experiences in accessing successful referral interventions (Funk et al, 2010).

2.7. Summary of literature

The literature above highlighted various issues concerning rising existence of terminal and chronic illnesses in populations, with overwhelming work trends of caregivers encountering different lived experiences that accounted for the increases in the need for Home-Based Palliative Care services. Various scholars all pointed to the fact that caregivers' existence in the area of Home based palliative caregiving could be understood in line with various roles caregivers play at different levels and different times and how these roles could be fulfilled in the caring pathways.

The scholars from the above literature gave an account of Home-Based Palliative Care requiring resource support services in terms of money, manpower, materials or logistics to use; time to work and technical support in form of information. Whereas understanding caregivers' psychological experiences; where literature talked about things of the mind like emotions, feelings have also been revealed by different literature scholars in various settings, but under palliative care. Opportunities that caregivers obtained in various settings of palliative care like employment opportunities, various types of rewards have also been highlighted. Caregiving and its challenges in various ways such as caregiver burnouts, and many others have been drawn from diverse encounters and settings. This literature inspired the researcher to formulate specific objectives based on similar areas but looking at lived

experiences that the Ndola caregivers could have encountered. It is from this that comparisons will be made with findings Ndola caregiving produced.

Scholars from the American Academy of Hospice and Palliative medicine encouraged stakeholders in programs for PC to expand the vision of care by adding community-based palliative care models to the list of caregiver's initiation programs. This was meant to advocate for their development and integration into other models of health care delivery; to enhance their knowledge base through trainings. These could be plans meant to operationalize care Improvement's in a "Triple Aim" care concept of: improving the patient experience of care (including quality and satisfaction); improving the health of populations; and reducing the per capita cost of health care (Gadbois et al, 2017).

This study reveals that once this is done, patients and their families can in turn have access to care options that best meet their individual needs as a goal (Twaddle et al, 2007). It is clear that volunteer caregivers make substantial distinctive contributions to community care outcomes underpinned by their unique relationship with patients, relatives and the community (Hill et al, 2014). These discoveries point to the need for mediations to support caregivers through policy improvement and strategies to improve health care provision including psychosocial support for caregivers.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Study Design

I used the phenomenological design for this study. Phenomenology is a philosophical investigation and description of conscious experiences without reference to the question whether what is experienced is objectively real; a qualitative approach with intentions to explore the lived experiences of individuals and groups (Creswell, 2007). I used this method to provide a means to uncover deep understanding of the caregivers' experience perspectives as regards the support services they used to receive; their personal psychological experiences; determine the opportunities they derived out of the Palliative caregiving process and challenges they encountered during caregiving. The way they observed the process of PC was done by examining and clarifying human situations, events, meanings which revealed various opinions and perceptions as designed (Ibid).

3.2 Site Location

The study was conducted in Ndola district on the Copperbelt Province of Zambia. Ndola caters for a population of more than 400,000 people. The respondents were drawn from four health facilities under Ndola District Health office; in particular Chipokota Mayamba, Twapia, Chichetekelo day care, and Chipulukusu centers catering for high density townships. These sites were regarded as important because they underwent transformation from the general HBC program to HBPC programs through orientations done by Tropical Health Education Trust (THET) project from Uganda and other stakeholders like PEPFAR through the PC Linking Project, in a 3 year partnership. It was an initiative to drive Ndola PC growth into the community with the aim of strengthening and integrating PC through a public and primary health care approach (Mackuline, 2015).

3.3 Study population

The study population comprised of caregivers 18 years and above who involved in Home Based Palliative Care programs nursing illnesses such as cancers, HIV/AIDS and other NCDs at health care facilities in Ndola district.

In order to identify the caregivers with these characteristics, discussions with the In-charges of various Health centers through the Ndola District Director of Health was done who

assisted with the names of Home based caregivers who were orientated in Home Based Palliative Caregiving who were available and active.

3.4 Sample and sampling procedure

The sampling approach which was used to select the sample was non-probability purposive sampling. It was conducted because respondent's characteristics were defined. In this study, the respondents were of a homogenous group with similar characteristics: both males and females practicing home-based palliative caregiving; who were above 18 years of age at the time of interviews, an eligible consenting age; they were non-professional caregivers, but trained in home-based care; also oriented in palliative caregiving; had been practicing as caregivers for 2 years and above, and are still practicing in HBPC programs to possess characteristics of lived experiences.

These were also people who had been living within these catchment areas of operation. They were selected from Health facilities which offer home-based and palliative care services which underwent community sensitization of triaging PC from Ndola Teaching Hospital to the community by the PC team under the THET project and other stakeholders such as Ndola Teaching Hospital PC team of experts.

3.5 Sample size

Fifteen (15) out of one hundred and forty (140) caregivers who were orientated were identified by the Ndola Director of Health with the help of facility In-charges and the Neighborhood Health Committee members. Twelve (12) HBP caregivers out of the fifteen were currently working then and met the criteria of being interviewed and interviews were on going until saturation was reached. The respective number of respondents found in each of the four (4) cited facilities; Chipokota Mayamba, Chipulukusu, Twapia clinics and Chichetekelo day care center. These received PC orientation by Ndola Teaching Hospital PC team in collaboration with the THET project from Uganda. The twelve (12) respondents were all enrolled and interviews went on until saturation was reached and data collection was discontinued (Natasha et al, 2005).

3.6 Data collection method

In order to understand fully the experiences of the caregivers In-Depth Interviews (IDIs) to respondents in this study were used. Face to face interaction using probing questions with an interview guide containing Palliative Care package in relation to the objectives provided in this write-up helped HBP caregiver respondents rebuild their experiences. These were in line with opinions regarding support, perceived opportunities, psychological experiences and challenges encountered during program operations, processes and what they perceived as better modifications to the program. The direct contact gave this researcher utmost opportunity of deriving ideas, feelings and remembrances in their own words and gestures.

3.7. Research instruments

The data capture instrument that was used was an interview guide, a digital recorder for responses and note taking to take care of other observations from non-verbal responses. The interview guide contained open-ended questions to provide a huge foundation to allow respondents express their views. All the responses were digitally recorded to ensure accuracy and credibility of data and no respondent at this point ever objected to digital recordings upon being informed of its usage and importance. In facilitating accuracy and credibility, the researcher avoided dependence and call to mind remembrance which could have resulted in missing out on vital information by taking down notes simultaneously with the recordings.

Digital recording in this phenomenological study design was necessary, because there was a lot of story-telling which brought about emerging questions and sought clarity through probing. Therefore recording was important to this study to keep track of the data in case of referring to it from time to time.

3.8. In- depth interviews

In-depth interviews were done engaging open-ended questions which provided a huge foundation to allow respondents express views of detailed information on perspectives of home based palliative care experiences. Mainly questions were asked around issues of resource support services experienced, personal psychological experiences, opportunities experienced in their work including challenges encountered in the community. The comprehensive information collected in the course of IDIs described caregiver's understanding on these issues. The respondents were free to express themselves in languages of their choice and in this study Bemba and English were preferred and used interchangeably.

3.8.1 Data Management and Analysis

Data management was done after every single session. This involved correctly labelling of interview notes with numerical codes to maintain order, de-identify respondents to maintain confidentiality. A verbatim transcription was done on recorded information by writing it out from recordings without changing anything in full text. Then transcribed text was read through thoroughly and reflected on; Cleaned through a technique known as '*Data Quality Control*' by member checking for inaccuracy and uniformity; completeness of responses; logical inconsistencies were also dealt with and corrected through clarifications from the respondents. Missing information from the data was addressed at this point. Translation of the transcribed text was then done because some respondents used both English and Ichibemba languages.

After acquaintance with the data, generation of preliminary codes (small units) followed which directed probing for themes amongst codes. Studying the themes, describing them and specifying the themes followed. Describing and organizing of the responses into thematic categories for analysis aided in transferring investigations from a comprehensive analysis of data in the direction of realizing shapes and emerging themes (Boyatzis, 1998).

Therefore "Thematic analysis" was the approach done to transform information in a process of "encoding the information". Words and phrases that served as labels for data were developed to create summaries of data categories. Manual coding was employed on commonly repeated words, expressions, significant statements, thoughts, feelings and viewpoints in the texts that seemed to address research objectives. These became sources of codes that created pattern networks (Boyatzis, 1998).

Thereafter explanations of each named thematic section and its relationship to the research question and objectives followed as: resource needs, psycho-social experiences, opportunities gained, and caregiver's duty, team work and career development. These interpretations linked information flow amongst themes accounting for the negative and positive experiences of HBP caregivers.

3.8.2. Data validity and Reliability

Validity characterized by the strength and rationality of the study were accomplished through member checking by asking the interviewees to listen to the audio recordings, read the transcript and verify recorded responses from each of their responses to confirm the

authenticity of what they had said during the interview process. The researcher further sought for their remarks and clarifications. The researcher similarly guaranteed the strength and rationality of the study by not doctoring the study process. This research's' reliability constitutes trustworthiness' and dependability which had been achieved by making comparisons of findings with some of those existing in research and its reliability was also based on aspects from sureness of the researcher concerning the certainty of results founded on the research strategy and context of the respondents involved.

3.9.0. Ethical considerations

3.9.1. Approval

Ethical approval and clearance was sought from University of Zambia Bio-medical Research Ethical Committee (UNZABREC) reference number 031-06-16, and the National Health Research Authority at Ministry of Health Headquarters – MH/101/23/10/1 to render the study legal and protect the respondents' wishes and rights; Written Permission was sought and positive written responses were obtained from the Copperbelt Provincial Medical Office - PHO/CB/53/2/9 and Ndola District health authorities respectively to carry out the study in respective stated Health facilities.

A pre- visit to the respective health facilities for familiarization purposes was done as a strategy to meet and know the respondents; this gave the researcher a great opportunity to create rapport, assess the environment for suitability of venue for interviews, establish the best language which could be used during interviews and also got to know other social norms that could be followed to attain mutual understanding and maximum cooperation.

3.9.2. Respect for participants and Autonomy

To fulfill the ethical principle of 'respect for persons', during recruitment and participation in this study, respondents were not coerced into taking part in the study.

Instead they were recruited on the principle of voluntary participation. They were fully informed about the purpose of the research as to elicit in-depth information on PC giving in the Ndola community; Procedures such as collecting data using a digital recorder was explained to them and an assurance was made on its safety so as to allow them make autonomous decisions in participating or not. Length of participation time was also mentioned (30-60 minutes interview on one participant) and that they were at liberty to agree

to participate or withdraw from the study any time they felt like doing so without being intimidated if they felt uncomfortable with the study at any point.

3.9.3. Informed consent

Participant information sheets were filled in and signed on a daily basis at onset of the discussions as well as obtaining of signed consent forms after respondents returned for the discussions as scheduled. This was after they asked questions and sought clarity during the process of receiving a repeat of the detailed information about the study as outlined in the psychological care component. Assurances which included information on some risks like reliving the horrible past in participants during the course of recounting their experiences and some benefits like community health promotion were also highlighted so that the respondents could make an informed choice to participate or not participate in the interview.

3.9.4. Confidentiality

A conducive and private environment for the interviews was provided and secured at the health facilities by In-charges in offices with no traffic to ensure privacy. Assuring respondents at onset of discussions that information obtained from them could be kept in confidence was done because it involved disclosure of sensitive information that could affect them and put the subjects at risk of suffering ridicule from society when exposed. Hence, the data was treated with high levels of confidentiality from the point of collection. De-identification in this case of such respondents was done and all field notes and transcripts were kept under lock and key with password to computer software stored data withheld.

3.9.5. Psychological care

The aim of psychological care was to fulfill the ethical principle of ‘beneficence’ which requires a commitment to minimizing risks associated with research. These could be psychological anxieties from questions asked which could have induced negative feelings and emotions of reliving the horrible past in respondents during the course of recounting their experiences. Respondents were given psychological care by being told in advance that this study would maintain confidentiality of sensitive information about them. In case the client would break down during the interview sessions, counseling could have been offered, then if the respondent seemed not to be getting over their anxiety, a break off the interview could have been considered and reschedule the interview to an appropriate time when the respondent feels relieved and becomes stable to the satisfaction of the investigator for a

smooth process free from negative feelings or otherwise if the situation remains the same the interview could be discontinued.

3.9.6. Dissemination of information

They were also told about the breach of confidentiality at some point, as information would be given out to all important stakeholders for usage in the public domain as a benefit to foster health promotion and enhance community development as this was the sole purpose of using them in this research. This allayed any potential anxieties to be and served clients an opportunity to make informed choices of whether to participate in the study or not.

CHAPTER FOUR

FINDINGS

4.1 Introduction

This section offers a qualitative standpoint owed to the exploration design that was pursued in investigating the lived experiences of Home-Based Palliative Caregivers of Ndola district. Firstly a general summary of the findings will be outlined with demographic characteristics of respondents highlighted in a narrative and table form. This will be followed by a table of themes in relation to the defining objectives and experiences quoted from caregiver's direct responses.

4.2 Respondents' Demographic characteristics

The following details are the demographic particulars that characterized the home-based palliative caregivers who were interviewed: R06 was 28-male from Chichetekelo day care Centre, R05 was 45-female from Twapia clinic, R04 was 49-female from Twapia clinic, R01 was 57-female from Chipokota Mayamba clinic, R03 was 57-male from Twapia clinic, R02 was 59-female from Chipokota Mayamba clinic, and R07 was 65-male from Chipulukusu clinic.

Table1. Respondents' Demographical Characteristics at theoretical saturation level

Age	Sex	Marital Status	Educational Level	community service (in years)
28 years	Male	Married	Secondary (Grade 12)	2 years
45 years	Female	Widow	Secondary (Grade 12)	14 years
49 years	Female	Widow	Secondary (Grade 12)	26 years
57 years	Female	Widow	Secondary (Form 3)	20 years +
57 years	Male	Married	Secondary (Form 5)	23 years
59 years	Female	Married	Secondary (Form 2)	15 years +
65 years	Male	Married	Secondary (Form 2)	5 years

Table 2 below was created from responses given by the respondents forming patterns of themes outlined in the table below.

Table 2: Themes

Main themes which emerged from caregivers' responses that will be explained in respect to experiences were based on the objectives of this study and sub-themes comprising quotes were as follows: resource needs, psycho-social experiences, opportunities gained, and caregivers' duties, team work and career development.

Objective 1: Describing resource support services experienced by HBP caregivers in

Ndola.

Major theme

Sub-theme

Resource needs

Limited Supplies from stakeholders

- Inadequate kits (containing gloves, antiseptics, bandages, cotton wool etc)
- Patients' failure to acquire medication
- Lack of Food supplements;
- Stationary challenges (Registers, referral forms, pens, etc)
- Lack of Facility transport (Ambulance, Zam-bicycles)
- Lack of Money (for booking taxis)

Objective 2: Exploring personal psychological experiences of HBP caregivers in Ndola

Major theme

Subthemes

Psycho-social experiences

Community acceptability

- There is respect from the community members
- Social status of caregivers is high in their community.

Individual feelings

- Emotional and Spiritual well-being (due to trust in God and from self-satisfaction from work they do)
-

Objective 3: Determining opportunities experienced by HBP caregivers in Ndola from HBPC practice.

Major themes

Sub-theme

Opportunities gained

Rewards obtained

- Knowledge from field work and basic orientations undertaken
- Self-esteem
- Hope for employment, incentives & further training to progress their vocation.

Objective 4: Establishing challenges caregivers experience during caregiving processes in Ndola

Major themes

Subthemes

Caregivers' duties

Experience in the field

- Long working hours;
- Work over-load due to multiple chores
- Cost burdens on caregivers; and
- Patients' Non-adherence to treatment
-

Team work

Experiences with fellow caregivers

- No support from colleagues;
- Working in isolation- no unity and;
- No collaboration with PC experts

Experiences with family caregivers

- No co-operation;
- Failure to regard advice;
- Neglecting & stigmatizing their patients

Career development

Knowledge/skills improvement

- Lack of intensive training in Palliative care
 - No refresher orientations in Palliative care
 - Lack of technical support and supervision
 - No palliative caregiving guidelines
-

4.3 Resource needs

4.3.1. Experience with stakeholders

This section will present support services given to caregivers by various stakeholders. Resource needs theme was guided by objective one (1) which states: “To describe resource support services experienced by HBP caregivers in Ndola”. Stakeholders could be within the community or outside the community.

4.3.2 Limited Supplies for caregiving

The caregivers said cancer and other life limiting illnesses had been involving significant upkeep and need for provisions of palliative caregivers using various materials. They however said most care needs were unmet because most of the Home Based Palliative Caregivers who offer them the care lacked sufficient materials to use because of limited supplies in the health facilities, as well as from both internal and external stakeholders. The most important material resources they talked about were clinical logistics, drugs, food and stationary. A concern was raised by one caregiver:-

...We do have material help from some well-wishers sometimes, not always. We receive various items to use, though of course the items are not adequate and do not last long because we do not determine the amount of donations to be donated, what to be donated and when they must be donated. Sometimes we receive items we may not need very much and lack things we always need to use all the time. So in short what I can say is the support services from donations cannot be reliable.

4.3.3. Inadequate Home-Based Palliative Caregiving kits

The HBPC's said they have passed through hard times to try and fulfill their obligations of caregiving as it had been very difficult for them to effectively offer quality of care when they couldn't afford material resources to use.

They cited an example of them not having even been able to carry out certain simple procedures like wound cleaning and dressing for patients with wounds because they had not been able to receive items like gloves, bandages, antiseptic solutions and the basic items that come along with the HBC kits. The common sentiment expressed by a 59 year old female caregiver is:-

...There are many, many things we don't have, just to mention a few, like gloves, bandages, jik / dettol, soap, umbrellas, raincoats, identity cards, aprons or coats and bags. We have work to do but we do not see all these things and just use whatever is available even if it's not ideal.

Findings in this respect indicated that clinical materials had not been readily available for caregivers to access because of failure and willingness within communities by individuals, families or organizations such as some non-governmental organization to donate some of the materials or money to procure.

4.3.4. Patients' failing to acquire medication

HBP caregivers said some of the materials could also be obtained from the hospital for instance: Essential drugs, Anti Retro Viral medicines and other drugs for opportunistic infections. This study revealed that despite patients being discharged from hospitals and hospices on medication, drugs to continue therapy at home were not easy to acquire for patients from such designated institutions. A 57 year male caregiver who most of the times also operated from the clinic dispensary had this to say:-

...acquiring drugs is difficult especially in getting drugs from here taking them to the patients; at the same time you find that we have got limited types of drugs to take. Morphine for severe pain relief for instance is not easy to get by because it has a cumbersome procedure to follow at the hospital because it is not readily available in the clinic facility, so we get discouraged to follow it up even if we know that patients require it. So that is what we go through apart from other problems like: lack of logistics like soap, gloves, protective clothing.

The study revealed that caregivers also said many patients defaulted for some time and deteriorated in condition and as such it was caregivers stressing for caregivers to especially in try to restore good health for clients who had treatment failure.

4.3.5. Lack of Food supplements for chronically ill patients a huge challenge

Results from all the respondents exposed this as a huge challenge in the name of food supplements like soya meal or Heps, beans, maize meal, cooking oil and so forth for patients' nutrition.

They said patients become too weak to fetch water or fuel to cook; or run errands to do shopping; or work in the fields to produce food. Thus, the patients depended on them as caregivers for such material resources required to assist in smooth caregiving.

...The problems we face for now, when the economy is bad, is feeding, there is no money to buy food for these patients and yet one of the most important messages they receive at facilities is “eat before you take your drugs”. Lack of food makes us also feel bad because many of their caretakers do not work and each time you ask about what the patient has eaten, the answer is nothing. Shortage of water is also another problem, we fetch for it from afar.

4.3.6. Stationary challenges (registers, folders, pens, paper etc)

The HBP caregivers in common findings said they were unable to document the activities they used to carry out on outreach home caregiving. Yet documentation was a practice they believed could help in providing evidence for what they used to do and could also offer a basis for advocacy on support in various areas. They said all types of stationary was not available such that even when referring patients for continuum of care, they sometimes just used to do it by word of mouth. This is because there was no paper for referral forms designed for caregivers. The following was an explanation by a caregiver:-

...Before referring patients we have to consult a nurse on what is assessed, if we decide to refer the patients to the health facility for administration of such drugs like morphine or other services, we go with the patients physically by escorting them to the health facility so that we explain the situation to the nurses. This is because the community referral forms have run out and we no longer are provided with plain papers to photocopy or just make some. It is even difficult to remember because no records are kept.

4.3.7. Lack of Facility Transport

The caregivers said this has been their source of worry in that they have encountered serious problems when referring patients for continuum of care in time. They said the Zamu bicycle ambulances that Ministry of Health had been provided for outreach services and effecting referrals within catchment areas had broken down irretrievably since no repairs had been done, nor had replacements been made.

The study further revealed that caregivers had ended up begging monies from all over their community to help transport their very sick patients to hospital or health centers a trend they said they were not happy about. A 69 year old male caregiver elaborated on this.

...In the past we used to have bicycle ambulances, but since they broke down, sure, there is no transport. Therefore, I just shoulder lift my patients and start walking with them slowly to the health facility. Sometimes for those who are unable to walk, we use wheelbarrows; sometimes if relatives have money they book taxis, if they don't have, we ask from well-wishers for donations and sometimes we involve our ward counselor for financial assistance if things go to the worst.

The caregivers in HBPC programs said they had to walk long distances in terms of their catchment areas as well as distance in managing the huge catchment populations and they said this had denied most of their clients and patients some services. They said the time they spent in walking to cover long distanced areas was too much to serve all the patients. The common explanation that characterized this issue was explained by 57 year old male caregiver:-

...in case of visitations to faraway places like mabunga and Roma where it takes us about two to three hours just walking, such that by the time you reach that place, you are tired and only visit briefly. We walk for many hours to do visitations and spend the whole day there because you reach there around twelve and leave late without food. This does not give us an opportunity to see many patients, so we just see may be two patients and for the others we make follow up appointments at later dates.

4.3.8. Lack of money

Results reviewed, indicated that HBPC's had inadequate financial support from both outsiders and inside stakeholders to help in proper service delivery especially enhancement of referrals between different care providers. They also cited this as a drawback in care and support to their efforts as care and support services provided to PLWHAs. The 57 year old female caregiver now narrates:-

...Some situations we find in the community demand that we just donate money so that, we buy the patients some items to use even if we also lack in many ways. Personally when doing visitations I secretly carry small parcels of mealie meal on

my back in a chitenge wrapper as if it's a baby and deliver secretly when I don't have money to spare.

This study revealed collective sentiments from HBP caregivers that to them money could have been a significant means to provision of quality and adequate Home-based palliative care services because ailments like AIDS and cancer are long, costly and debilitating diseases which required those caring for the sick to access such. Unavailability of money resource rendered the affected (family and caregivers) and infected incapable of buying goods such as food, clothing, drugs and other materials for wellbeing.

4.4.0 Psycho-social experiences

4.4.1. Experience with the community

This theme of psycho-social experiences emerged from objective two (2) requiring an exploration of personal psychological experiences of Home-Based Palliative Caregivers where they narrated how they viewed aspects of living in the community and how working for the community was; whether they felt accepted by the community in terms of respect and regard accorded to them in society. They expressed their emotional feelings too in various instances and what prompted them to feel that way.

4.4.2. Community acceptability

In this section the researcher will reveal findings of the HBP caregivers' view-points on how the community had taken their presence in PC processes; whether they received respect or not for helping out and how the community generally received their contributions towards this work and what caregivers' individual feelings about the process of caregiving were.

4.4.3. Respect and social status

Caregivers felt they were treated with high regard by addresses such as “**Mother, Doctor or Papa**” terms leading bringing about dignity & sense of self-worth according to the caregivers. This to them showed them a high level of trust and dignity community members had for caregivers and this made the caregivers feel respected so much to even go an extra mile in working even at night to meet their client's needs. The caregivers said they enjoyed a cordial relationship with the patients as well as the community at large. Results revealed that patients preferred to confide in them than their own relatives when they needed help. Reference was sought from the following narration:-

... Above all, the respect I receive “fyani (grass)” big respect from the people in the

community because I have allowed them to seek for help from me even at night and I welcome them. If possible I accompany them to escort them to the clinic no matter what.

Findings disclosed that the caregivers felt the people they serve in their community regarded them as very important people they recognized them and consulted them on decisions pertaining to their sick relatives; they said this was because they had been their custodians of their health, such that they even addressed them as Doctors. Here is a revelation:-

...people address me as a Doctor except I ask where they have seen the papers of me being a Doctor and I keep on reminding them that I am not one although some (mostly taxi drivers) also call me mother to panadols (bana panadol); they express happiness upon seeing me, they will even ask my absence in the certain days. Then I tell them jokingly also that I went looking for working tenders. They will then complain to say you want us to die with your absence.

4.4.4. Individual feelings

The findings of this study revealed how the HBP caregivers had expressed their minds in psychological views towards what they do. They brought out their stand on each and every point that this research sought to understand. These views were in line with their emotions and spiritual well-being which outlined their sentiments as follows:

4.4.5. Emotional circumstances

What was discovered from the investigations were that caregivers went through psychological and physical difficulties stretching from anxiety circumstances especially when the demands made on caregivers turned out to be bigger than their skills could manage in some instances. They said it had not been easy to control and reduce their anxieties though, but they said they had pulled through and managed to contain their feelings in positive ways due to the passion they had for their vocation especially their consideration to save lives of their brothers and sisters in their community. They said at times disappointments had rocked their experience from a few careless members of the community who talked anyhow, but they had managed to be emotionally stable and went on doing the caregiving diligently because they understood the behavior of sick people. One common expression from made by a 45 year old female caregiver had this to say:-

...I have never felt emotionally stressed or depressed personally because I understand human beings especially the sick; although sometimes we are teased and treated badly, like

at one place where we were invited to visit a patient after relatives complained that she never wanted to take drugs or come to the clinic for medical attention.

Just after we introduced ourselves as palliative health care givers who had gone there to see her, she went inside the house, got a dish of water and poured on us the water with a lot of anger for what she termed we went there for gossip.

4.4.6. Spiritual well-being

Findings are that the caregivers had strongly believed they have a God driven motivation to succeed in what they do for their patients. They said their biggest reward apart from the ones they mentioned will come from God and they also made an emphasis that what they do is meant to please God and not human beings. The 69 year old male caregiver reveals:-

.... I feel good the fact that I don't work to please ordinary people, I work for God and I draw strength and comfort from the trust I have in God because my aim is to help patients who are in pain to feel better; reduce on the numbers of diseases and deaths in this community through counseling and I feel okay about it because I know that it is God alone who will reward me.

4.5 Opportunities gained

This theme as highlighted already was guided by the third objective: “To determine opportunities experienced by Home-based Palliative Caregivers in Ndola from the Palliative caregiving programs. The caregivers explained that they realized beneficial rewards which are motivating to them in executing their duties regardless of them facing some challenging experiences in some areas.

4.5.0. Rewards in caregiving

The caregivers said despite them having had undergone a lot of challenges in the process of caring for the chronic and terminally ill patients, they also had attained rewards in form of recognition, respect and knowledge acquisition.

4.5.1. Knowledge gaining

The study discovered that caregivers acknowledged that, regardless of not having been technically trained like professional caregivers to enhance their skills of proper and tactical knowledge base, they admitted that the initial PC orientation, through the basics they underwent, some level of knowledge had been acquired.

They said they had been managing to execute their duties diligently and could count on the basic knowledge as a benefit. Their common explanation went as follows:-

.... Each time I consult from others, be it my fellow caregivers or the nurses on things am not sure about in the field, I learn new things and I say knowledge is an achievement, because the knowledge gained is not only used on patients but also for my personal gain and my family as no one will take it away from me. There are certain skills which I would use even after leaving this place so I don't regret having been involved in this program. "Knowledge is power", and I will die with it

4.5.2. Self-esteem

The caregivers said making impacting decisions on people's health/lives which in the end yields good quality of health or good end of life (EoL) which earns them recognition was a positive reward and had brought them individual growth, self-satisfaction, and positive feelings during palliative care regardless of their distinctive and taxing situations.

The findings disclosed that they exercised integral deepened pride due to self-actualization. The 45 year old female caregiver explained:-

.... The care I have been giving has been dependent on my commitment to care and I have been able to offer it adequately because of what I have based my actions on; wanting others not to go through what I personally have gone through. So my experience is that I have done well in caring for the sick voluntarily without getting any ngwee just depending on the mercy of God that one day we will be rewarded by him alone.

4.5.3. Hope for Employment

Results of this research revealed that some caregivers had been able to win some job opportunities in some caring institutions on recommendation by the community through the eyes of the community, Neighborhood Health Committee representation after being recognized as hardworking, committed and knowledgeable. They said this move cheered them as HBP caregivers and further revealed it as having been a common anticipation by most caregivers. 28 year old male caregiver disclosed:-

..... Some of my relatives and friends have been telling me to look for a job in big companies or banks because of my background of some accounting certificate course I did some time back. But even what I do is a job because the Government has since placed us

on the payroll me and my three other female HBPC colleagues since the Centre is now partly under the District Health Office care after the private hands stopped operating it.

Another 57 year old female confirmed the said anticipations on need for job opportunities.

...The other suggestion is for Government to consider employing some of our children who personally I have involved in learning to care for the sick and are doing well, because some of us are growing older, very soon I will be 70 years of age because am already 57 nearing 60 years which is not far from this and will not have that energy to carry on with this work.

4.6 Caregivers' duty

4.6.1. Experience in the field.

This section will describe another important theme that emerged with guidance from the fourth objective namely: "Challenges HBP caregivers encounter during caregiving processes in Ndola". It was another area where negative experiences had been mentioned; Caregivers' duty under with experiences of long working hours; work over-load due to multiple chores; cost burdens on caregivers; and patients' non-adherence to treatment.

4.6.2. Long working hours

This study revealed that most of the HBP caregivers spend more than two to three hours at each visit which they say is quite a long time for daily outreach services. They said they are compelled to work long hours because of the overwhelming needs of the patients they come across which need to be attended to. The 59 year old female caregiver narrated this:-

...For daily visitations, it is about two- three hours or more depending on the distance being covered because we have to walk to some far flanked areas like Mabunga where some patients live and it also depends on what works are required to be done when you are there. This is because we just don't visit to look at somebody's face, no, we also take time to talk to the people around and if we find them busy, we can even spend more time than 2hours have mentioned as we have to give them respect by waiting for them to finish whatever they are doing.

4.6.3. Cost burdens on caregivers

The study showed that almost all the caregivers incur some expenses in trying to meet some important needs of their patients. They said the chronically ill patients have needs

which require money most of the times and these are people who do not work and are being kept by families which fail to provide fully for them. The caregivers regardless of not earning salaries or other monetary incentives, said they had been sacrificing the little they could afford meet some of their patients' needs. One caregiver had this to say:-

...That is why I told you earlier on that most of the times I just have to sacrifice the little portions of food that I also have or give them 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.

4.6.4. Work over-load due to multiple chores

The HBPC's said they did not operate with defined roles and especially that there were a lot of needs and things to do as situations demanded; they were exposed to a lot of work. The caregivers said they were always overwhelmed with numerous tasks in that most of the patients they cared for were not able to self-care due to terminal conditions and sometimes their family caregivers abandoned them and left them alone as justified by the 57 year old female caregivers' narration in the following scenario:-

... there are a lot of things to be done most of the times, feeding patients; or even fetching for food where we make movements to and from to buy at the market or a nearby stall (kantemba); not only that, there could also be need to bath the patients, do some chores for the patient like, sweeping, doing laundry and cook, then leave, so it is a lot of work especially that we are few.

4.6.5. Patients' non-adherence to treatment

The investigations revealed that during outreach caring services, patients' non-adherence to treatment was common and caregivers attributed the non-adherence to treatment mainly to lack of food which they said was a big challenge. On the other hand, particular drugs required to be purchased; they said because it's not all the prescribed drugs that are provided at facilities, patients defaulted and this had serious challenges on process in terms of patient's improvement and could not decrease work over-load because patients deteriorated.

. The following is a revealed sentiment by a caregiver:-

...Madam we don't get paid as volunteers to afford drugs not available, but we are only able to help these patients when they are in need most of the times; like in terms of food when doing visitations we discover they stop taking medications because the drugs they take most of them are too strong to be taken on empty stomach so as caregivers it's difficult to leave or let the patients end their medication just like that. We look around from what we have and spare for the patients.

4.7. Career development of Home-Based Palliative caregivers

An important theme directed by the fourth objective and in this segment the investigator will present outcomes of the HBPC's perspectives with regard to what they thought could have improved their career in caregiving through knowledge and skill improvement.

...It is also important that we receive some support to take our career of caregiving upwards so that others can see it as an important career and join.

4.7.0 Knowledge and skill improvement

One of the most important instruments that caregivers said they had always been looking forward to in order to fulfill the dream of advancing their career of caregiving to a better level in the Palliative Care program was a moment when they could be given more new knowledge and skill improvement through: Intensive training; Refresher orientations; Technical support and supervision from experts with availability of printed and detailed Palliative Care guidelines to follow. Justification is from the discussion below:

4.7.1. Lack of Intensive training for Home-Based Palliative caregivers

Findings based on common understanding revealed that intensive training during the transformation of Home-Based Care (HBC) to Home-Based Palliative Care (HBPC) never took place. What HBPC's said they went through was merely an orientation of PC basics. According to them this could not fully enable them to handle chronically and terminally ill patients skillfully and they said they could not be able to manage complicated conditions, severe side effects of certain drugs because they relied on using their initiative.

These were some of their sentiments:-

..... No serious training has ever taken place so far apart from the first orientation workshop we had on palliative care a long time ago. I can't even remember the date, and it has been long because ever since Ms. Rona Mambo who took us in home-based care went, everything came to a standstill. So whatever little she taught us, that is what we are still applying in our practice.

4.7.2. No Refresher Orientations in Palliative Care

The caregivers said they have been neglected by relevant authorities because apart from not having been given intensive training they also have never been re-oriented in what they do. They said the knowledge from the past was outdated and this is what they are still using when times and technology were advancing. The following was a caregiver's reveal:-

...This is why I have said in the past things used to work well. It has been long since we received the first drill in Palliative care and we have never seen anyone come back to offer us some refresher course or even just making a follow up to see how we have been working. They don't even know if we do the correct things or not.

HBP caregivers said care of these patients had not been easy for them because most of the times it has not been easy to consult the qualified clinic staff when stuck on certain issues whilst in the field the reason being; to get back to the facility to do so had proved to be time consuming for the caregivers due to distances and the workload involved.

4.7.3. Lack of Technical support and supervision

Caregivers' said scarce information existed in context with enlightening them in symptom management, proper practice during hands on with some home-based basic procedures like wound dressing; proper referral of clients for continuum care to other service providers; as well as in addressing distressing symptoms in advanced disease and improve quality of health. Caregivers said to consult with each other on phone as caregivers only resulted in misleading each other without knowing. This is because no Palliative Care experts or their trainers had ever come along to approve of their activities and give advice where necessary:-

...Ever since we underwent the Palliative care orientation, we have never worked in collaboration with the trainers and other Palliative Care experts from Ndola Central Hospital who carried out PC community sensitization.

We depend on consulting expert caregivers from hospices about certain things we are not sure about. For big wounds, we seek for expert care at the health facility and if all goes to the worst like there is a patient now with infected above knee amputation, we have sought help from a male caregiver from Isubilo hospice in Chifubu Township to help with wound cleaning. This is not easy because sometimes he is not available.

4.7.4. No Palliative Care Guidelines

The caregivers appreciated knowledge obtained from the initial PC orientation as they said they were able to use it on their personal families apart from the patients in the community but said they depended on knowledge from other people's ideas whenever they wanted to make consultations in case of gaps or problems during caregiving because they lacked material support in terms of printed out guidelines from the PC experts for proper information to refer to. They had this to say:-

...Most importantly I would also love to see support in terms of literature to read, things like PC books, magazines you know. This can include DVD's for health videos which can play on our Television set and educate clients whilst waiting to be seen by the clinicians in our facilities. Knowledge is power you know.

4.8 Team work

Another major theme guided by the fourth objective from which emerged two subthemes namely: experiences with fellow caregivers and family caregivers where negative experiences characterized their work.

4.8.0. Experiences with fellow caregivers

Caregivers disclosed that regardless of being overwhelmed with work overload, they rarely found it necessary to combine efforts of working in collaboration. They said each one felt like they owned the patients allocated in their care. They said this was because sometimes some caregivers would only have a few uncritical patients who they could manage quickly and get on to their normal life whilst others would struggle with longer hours of care with critical patients. One caregiver narrates:

...there is no unity amongst us caregivers because people want to work the way they want especially if they are lucky with few patients who they cannot bath or feed, but if you are unlucky with very sick patients, you will suffer.

4.8.1. Experience with family caregivers

The HBP caregivers revealed that despite having been accepted in their community and being accorded the utmost respect, it was never easy at times for them to work with family carers because most of them seemed too busy in running errands outside their homes to the extent of neglecting patients who sometimes are left in hands of small children with no proper care.

They disclosed that this led to non-adherence to treatment because the patients could go on without food or access to drinking water to enable them take drugs. Some would even be locked up alone in the home an issue they said was so stigmatizing to the patients and worsen their conditions. Another caregiver narrates:

...if a patient who cannot manage self-care is locked up alone in the house, imagine, do you think this person can survive without fresh air, without food, without water? It is difficult to work because their family carers cannot take advice as we have been talking to some of them for a long time about how to look after their relatives, but they say, now if I stay home and not sell, are you going to be buying food for us?

CHAPTER FIVE

DISCUSSIONS

5.1 Introduction

In this whole chapter the researcher will discuss experiences outlined in themes that emerged from resource support services to Home-Based Palliative caregivers in Ndola; their personal psychological experiences; opportunities that have had characterized their caregiving experiences and also challenging experiences. Thereafter implications of the study will be discussed followed by the conclusion which will outline in categories of negative and positive experiences identified from the study and later make recommendations to inform policy.

5.2 Resource support services experienced by Home-Based Palliative caregivers in Ndola

The aim of this research was to investigate lived experiences of Home-based palliative caregivers in Ndola as regards the objectives of the study. This section will discuss findings that were arrived at in line with objective 1.

Whilst Jack & Kirton, (2012) identifies key motivation to becoming a volunteer in Uganda; revealing volunteers' expression of pride in work obtained from trainings, logistical support and inclusiveness in decision making, this study revealed that HBP caregivers and the PC program as a whole had received limited attention from government and other stakeholders in the health sector. Neither internal nor external stakeholders had given financial support to the PC activities or provide consistent material resources to improve the performance of HBP caregivers and improve quality of care to the patients which included quality End of Life with minimal risks was a challenge.

Addressing gaps of material support (stationary, printed guidelines, clinical logistics such as gloves, antiseptics, umbrellas, gum boots etc), financing (giving money) to institutions undertaking PC, understanding and taking suggestions, ideas of operations from the communities where these volunteers operate could absolutely help as opposed to the experiences revealed in this study where HBP caregivers who in their own social endeavors struggle to survive, but are the ones who have become sole bearers of costs for their fellow vulnerable. They count this as an unfair act in their experience.

In another study involving 10 HBPC service providers purposively selected with an objective to assess the status, inadequacies and prospects of care and support services. Results revealed that there had been inadequate financial support from both external and internal stakeholders to help caregivers in proper service delivery especially enhancement of referrals between different care providers for specialized care and other different social services (Zerfu & Yaya, 2012). This is to say timely referrals could be enhanced by addressing transport challenges through financing support and could enable clients receive continuum of care early enough if various structures or systems support the HBP caregivers and the PC program adequately.

Lack of consistent support to the HBP caregivers and the PC program could de-motivate them and result in serious caregiver drop out from the few remaining committed caregivers and this could backfire negatively on the institutions that offload chronically ill and terminally ill patients under home care in their communities with congested admitting spaces, work overload on their few staffing levels and compromise with quality of care to all the patients including the general cases and lead to high death rates in health facilities..

This confirms that financial/material support could motivate HBP caregivers to continue working prevent shortage of human resource as this would be an enticing incentive.

5. 3. Personal Psychological Experiences Home-Based Palliative caregivers in Ndola faced.

Literature reviewed revealed that where work overload attributed to stress, it was implicated in a wide variety of psychological/physical problems; anxiety states; emotionality situations especially when demands are more than the abilities to cope which became a burden on health care and support programs (Porter, 1999), it was the opposite with findings in Ndola where HBP caregivers expressed inherent satisfaction in caregiving despite challenges of inadequate resources & work overload. They said their passion to help the sick was something addictive and they said they worked with a conscious. They said if they didn't do it they felt guilt as if they were neglecting their own brothers and sisters.

The physical and emotional burdens of caregiving vary, as patients' disease advance to the terminal phase. This period is often characterized by intense disorder and extreme strain. In circumstances of persistent illness, terminal stages, or the dying process, HBP caregivers require to meet new encounters in dealing with growing functional limitations, increasing reliance of patients, and more symptom burden.

In cases where management was lengthened, the capability of caregivers to meet the daily needs of patients is rigorously tense and care providers of end-of-life care show experiences of increased emotional distress, especially when they are limited in their ability to participate in valued activities and interests. Research had suggested that caregivers of cancer patients were at risk of developing a variety of psychological and physical problems, including anxiety, depression, fatigue, reduced self-esteem, and somatic health problems (Kim & Given, 2008).

It is suggestive that the levels of the caregivers' psychological adjustment were cancer caregiving stress is concerned; management of meaning out of providing care is not easy to control and reduce such emotional stresses of caregivers (Kim & Baker, 2006). However in this study positive affect had characterized the existence of HBP caregivers' psychological experiences because they had commonly expressed the presence of God in their work for their emotional & spiritual well-being

5.4 Opportunity Gaining Experiences from Home-Based Palliative caregiving practices

Employment opportunities – the fact that some HBP caregivers at Chichetekelo palliative day care Centre had ended up being employed on full time basis and have since been placed on the Governments' central payroll, benefit results from caregiving became a reality to them and for some without jobs, it brought a lot of hope of being employed in future and this potential opportunity motivated them to even work extra hard. Literature justified that such outcomes are motivational & play a pivotal role in emerging programs to minimize mental & emotional suffering of caregivers. This benefits them in recognizing PC as a significant vocation (Braun & Clarke, 2006).

Findings also indicated that among rewards the caregivers unanimously regarded, were the short term training or basic orientation they had in PC as knowledge acquisition and the other trainings from other health fields as complimentary to the PC knowledge which enhanced support to HBP caregivers in giving correctly prescribed medications & other services properly as may be needed (WHO, 2002).

This was justified by World Health Organization (WHO) literature sentiments stating “wherever and whenever palliative care is provided, factors to be assessed include: affordability and the presence of health information for community care and support services such as guidelines and training for palliative caregivers. A feasibility study revealed the

capacity to intensify caregiver understanding and abilities associated to harmless movement and minimize risks when caregiving done using informative video watched when suitable for caregivers and patients. Practice of this DVD technology to tutor has confirmed effectiveness because accurate information aids in lessening uncertainty in areas like; the patient's illness or disease; symptom etiology; what to expect in the future; treatment of side effects; and management of medical emergencies.

This was because when patients choose to be at home, caregivers can be trained by professional health workers like Nurses and Doctors to effectively provide professional information to enhance support in giving correctly prescribed medications and apply other physical and psychological care services properly as may be needed (WHO, 2002).

To this effect findings suggest that positive affect is as a result of occupation prospects that arise besides rendering care for cancer survivors', quality of health for Aids patients and others. Such outcomes play a pivotal role in emerging programs to minimize mental and emotional suffering of cancer caregivers with numerous responsibilities. This benefits them in recognizing their caregiving experiences as significant (Braun and Clarke, 2006).

5.5 Challenging Experiences Home-Based Palliative caregivers faced during caregiving in Ndola

Work over-load due to multiple chores; long working hours; physical burnouts of other caregivers are some of the challenges that caregivers said had characterized their experience when carrying out activities in the community on visitations; Formal training had never been given to the caregivers and no re-orientations nor TSS & PA's to foster knowledge and skill improvement for caregivers had not been done too.

Furthermore, the program of PC lacked the spirit of team work due to caregivers working in isolation with no sense of unity; no collaboration with PC experts (NCTH) which resulted in work overload and no continuum of care. The issue of continuum of care had also suffered setbacks with transport challenges due to no money to use in booking taxis for transportation of drugs and referral of patients, long distance to care were also an impediment to good care; broken down Zam-bicycles had even worsened the situation. Lastly but not the least, limited supplies of material and financial resources also affected caregiving; where clinical logistics (gloves, antiseptics, etc) drug availability, food supplements, stationary supplies were concerned had been reported to be a challenge.

The HBP caregivers spent more time than they were supposed to at each visit during daily outreach services conducted which was too much time for home visits. This had translated into work overload because the caregivers had to shoulder the many gaps created by the absence and lassitude attitudes of family caregivers towards caring for the chronically and terminally ill patients. The family caregivers do not even regard advice given on caring for patients hence increasing on the many needs HBP caregivers have to fulfill for patients; physical burnouts the program has undergone by caregivers who were oriented in PC after realizing this is not a paying job and neither does it contain any direct benefits has led to less man power to help; especially also the fact that people in their community think it's mandatory that HBP caregivers must always take care of their patients in full because they get paid to do PC has contributed to neglecting of patients and leaving critical care in the few HBP caregivers hands.

Due to the same challenge, caregivers incurred expenses which no stakeholder took responsibility of reimbursing. Caregivers in so doing said they were just trying to meet some important needs of their patients which could promote good health or render quality End of Life. Caregivers, irrespective of not earning salaries or other monetary incentives said they sacrificed whatever they had to give service to their patients as outlined.

Hence the need to bring in programs which must focus on family Caregiving in palliative care (especially the extended family concept), supporting heads of families with social cash transfers or other income generating activities to empower them financially and materially to deal with relative poverty in their homes which destructs them from cooperating and adhering to advice on patient caregiving but instead leave patients alone and rush to run errands to earn a living; care giving roles & decision making; rewards, meaning & coping etc. these may be suggestive of knowledge building as regards family care giving for patients where family members are advised to work together with the volunteers and take a primary part in the care (Funk et al, 2010).

This kind of team work was also described and highlighted by New Rochelle, (2016) in the US who said: Providing end of life care had changed with the coming of Anti-Retroviral Therapy to using a holistic approach to Palliative Care which resulted in patients staying at hospices for shorter periods and eventually could return home to be cared for by their families.

Where strong family and community networks are already providing care, there should be support and specialist advice, support and education, which should be available both to HBP caregivers, family caregivers and to clients. This could work effectively to tackle work overload brought in by multiple chores when the care required is especially complex.

5.6 Implications of the study

This study was very timely as it is able to inform policy that promotion of palliative care services in the communities where people are of low Social Economic Status (SES) is inevitable. Policy makers through this study therefore, will be able to study how Home-Based Palliative Caregivers' existence can be revitalized (Hill et al, 2014). Most importantly, through informed policy, improvement to caregivers' existence and experiences in Palliative care services could be incorporated into the prevailing health systems which are operational and most justifiable way of reaching out to more patients and their families in need of Palliative care, and also offer continuum quality care and End of Life to those already enrolled in the program.

This will only be possible through the inclusion of palliative care into national policies to make it become national palliative care programs. This will potentially be through policy and strategy development, governance and leadership where political will is a core demand to facilitate palliative care education and training; ensure availability and access of medicines; capacity building of professional health and community care providers through technical assistance after integration of palliative care in existing health services which include public health facilities and Non-governmental health facilities to effect proper service delivery (APCA Annual report, 2013-2014).

Moreover, the information generated will fill the gap in the literature for HBP caregivers' experiences in Zambia, which had been characterized with scarcity of information; Caregiver's experiences on support needs through thematic analysis of experiences on resource needs have led into the identification of incentives and non-incentive resources which service planners could integrate at macro-level planning. This will in-turn yield programs addressing caregivers' needs and motivate more community volunteers join to promote greater community participation in caring for the sick and improve caregivers outcomes and their capacity to provide EoL as well as participatory community development (Aoun et al, 2015).

This possibility of doing internal assessment needs will inform and prompt policy to operationalize a HBP caregivers' Support Needs Assessment (CSNA) tool. An example, Western Australia has the CSNA concept in place administering questions that focus on the needs of HBP caregivers. This is a tool which guides in assessing emotional, social, financial & psychological wellbeing of HBP caregivers. Support accorded to Australian HBP caregivers is therefore based on the findings from this guiding tool (Aoun et al, 2015).

Eliciting in-depth information from caregivers' expressed experiences has highlighted that there are gaps in their knowledge levels especially that they are not formally trained to care. Knowing these gaps has served as a guide on what guidelines ought to be given to them by the PC experts so that both the caregivers and the patients are protected

This study could enable the Home-Based Palliative Caregivers to appreciate their existence as important stakeholders in the caring process of chronically and terminally ill patients after being involved in the study.

5.7. Conclusion

The process of organizing and sorting data with codes served as a way to label, compile and organize my data. This allowed this researcher to synthesize what was happening in the community by linking data collection and interpreting it. This then provided the importance to think about the caregiver's experiences big picture, by developing a storyline around their operations in the community". Essentially, the core issue was to bring out what emerged as common and unique themes from experiences pertaining to respective objectives of resources, psychological, opportunity and challenging experiences.

Findings of negative experiences revealed: lack of team work, limited resource supplies such as inadequate Home Based Palliative Care kits comprising medical and surgical logistics; lack of food supplements to boost nutrition and many more limitations. Caregivers' duties too were associated with: work over- load, long working hours and cost burdens. In addition to career development was lack of the following: training, refresher courses, technical support supervision and standard guidelines. Whilst positive experiences reported were: hope for employment; feeling respected and highly regarded in their community bringing dignity, sense of self-worth, self-esteem; and self-actualization associated to impacting decisions made on people's health. This study therefore contributes to growth of research on determinants of health, a basis for further research by students, academicians; researchers to bridge knowledge gaps and provide

evidence to inform policy in integrating caregivers' issues in a wider health care system and address health inequalities.

Exploration of caregivers' experiences in Ndola is a step in the growth of research advancing knowledge on determinants of health for populations in health promotion. This provides a basis for further research by students, academicians, researchers and policy makers on issues this study has not addressed or answered. Negative and positive experiences of caregivers are philosophical evidence to inform policy in integrating caregivers' issues in a wider health care system and address health inequalities. This study therefore has contributed significantly to the body of knowledge in palliative care issues in Ndola and as a point of reference to literature in Zambia by the built scientific evidence which has been explorative in nature and will inform policy; enable everyone to understand the role of Palliative Caregivers to the general population in a wider health care system.

5.8 Recommendations

- i. There is need to integrate palliative care in health systems of public health institutions and Non-governmental organizations such as Community Based Treatment Organizations (CBTOs) where community caregivers can work in collaboration with specialized professional health care providers like Ndola Teaching Hospital Palliative care experts with proper communication channels of continuum of care.
- ii. Palliative Care experts must be identified and urged to give Technical Support Supervision and Performance Assessments to Home-Based Palliative (HBPs) caregivers in various health centers and communities to indirectly re-orientate existing caregivers.
- iii. Formal trainings in HBPC to be done to existing caregivers so as to improve knowledge and skills to enhance proper caregiving.
- iv. There is need to extend social cash transfers to family heads of chronically and terminally ill patients.
These could help in income generating activities that will help in alleviating relative poverty and will help to provide food, reduce on patient neglect and improve adherence to treatment.
- v. There is need for Government and other stakeholders to introduce logistical support in and resources management training for clinical supplies and transport; bicycle ambulances and re-introduce food supplements for the chronically ill patients like

Heps, cooking oil, mealie meal, and beans and so on. This will improve nutrition of patients and enhance their treatment adherence and cut on expenses borne by the HBP caregivers.

- vi. There is need for infrastructure improvement by putting up an office or room for PC in all the Health centers with new technology of care and support facilities for IEC (PC books, magazines, leaflets, brochures, DVDs) and record keeping /storage facilities which can be used by caregivers and many more people in facilities.
- vii. Guidelines for both non-professional and professional caregivers must be provided in all health facilities.

5.9. Study Limitations

Though this study could be a point of reference on PC issues pertaining to most areas in a similar fashion, the findings in this study are not generalizable to populations outside the sample population; this study also focused on active HBP caregivers. It would have included those HBP caregivers who physically burnt out to obtain a greater perception of experiences of all HBP caregivers and lastly the face to face interviews may precipitate fear and hinder disclosure of detailed and relevant information. Hence the use of follow up and probing questions to supplement initial responses could have been bothering and exhausting too.

CHAPTER SIX

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APPENDICES

Appendix 1 Participant Information Sheet

Reading level 8.0

University of Zambia, School of Medicine, Department of Public Health

Study Title: Investigating lived experiences of Community Home-Based Palliative Care volunteers

Principal Investigator: Catherine Katentemuna Musonda

UNZABREC NO:

Purpose of research project

This is a study in which am doing a research in order to be awarded a master's degree in public health, health promotion practical area at the University of Zambia, School of Medicine, Ridgeway Campus, Lusaka. To get done with this, I will need to understand what the volunteers in communities go through (experiences) when caring for patients with long term diseases. When I complete doing the study, you will be told about the results and with your permission, the information will be shared with high public offices and the general public for acting to help in improving health services in the community. Therefore, I will ask you a few simple questions to which you will need to give answers from your experiences.

.Why you are being asked to participate?

I intend to interview home-based caregivers who give care to patients with long-term diseases in Ndola. You have been chosen among 15 other volunteers to take part in this study because you happen to have the right characteristics needed for the subject.

Procedures

If you agree to participate in the study, I will need you to sign a consent form showing that you have accepted to take part in the study. We will then sit together at a venue we will both choose for just 20 to 30 minutes to talk about your experiences. I will ask you questions using a question paper and will record the interview so that it helps me to remember information I may miss during the session.

If you will not be comfortable with the recorder, I will just write down your answers which may take long. The information you will give me will be noted down and later typed to make a document that can be read and understood, but your name will not be written on any document. In this questionnaire, I will ask you questions in the following areas: What support you have been receiving from stakeholders to help you in carrying out duties of caring for the patients with long term diseases in the community.

- I will need to learn from you on how you have been managing to care for the patients in terms of referrals when they are in need of care from other service providers outside your community.
- I will also ask you to explain the challenges that you have been facing when caring for these patients.
- I will also need to find out from you how you would want the program of home-based palliative care to improve by mentioning the things you feel should be done or should not be done?.
- Lastly I will need to understand what you think the benefits are to the patients with long-term diseases and the community by having the community home-based palliative care volunteers around, in health care in the community?

Risks/discomforts

You will not experience serious dangers by taking part in this study but Potential risks such as remembering your past painful experiences of nursing very sick persons is possible, which you may not want to talk about. However, you need to know that some sensitive questions that I possibly will ask you do not mean to injure you but to help guide solutions through policy makers so that in future such experiences do not happen again because they will have been prevented. Nevertheless, I would like to promise you that, not anything you will say in this study would be shared with everyone.

Benefits

You will need to understand that this research is not meant to benefit respondents directly, but to add to the body of knowledge that will enable you become knowledgeable in issues of caring for your community in health-related matters essential to improve community health.

On the other hand this can be a source of planning well for distribution of resources on health matters and achieve reduce on health inequalities in the community by stakeholders the information would be shared with.

Payment

Participating in the study does not attract any allowance apart from transport refund.

Protecting data confidentiality

Since all information from you regarding this study is highly confidential, it will be treated as such by not indicating your personal identities and I will possibly protect it by placing it in a lockable cabinet. It is going be kept for two years only as waiting time, thereafter it will be destroyed.

What happens if you do not want to participate in study?

The choice is yours. No one will force you to take part in the study. In case you feel like stopping if you are already in an ongoing study, you are very free to do so and no one will blame you or give you problems.

Who do you call if you have questions or problems?

Call me, Catherine Katentemuna Musonda

Cell no 09774888045 or 0950454189 Email: musondachaile@yahoo.com Call or contact the University of Zambia Biomedical Research Ethics Committee office for any ethical concerns. The Ethics Committee contact information is:

Address: The Chairperson of the Biomedical Research Ethics Committee, University of Zambia, School of Medicine, Ridgeway Campus, P.O. Box 50110, Lusaka.

Telephone: 260-1-25606 Fax: 250753 E-mail: unzarec@zamtel.zm

What does your signature (or thumbprint/mark) on this consent form mean?

Your signature (or thumbprint/mark) on this form means:

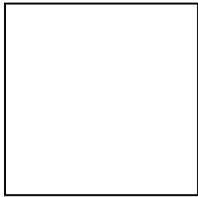
- You have been informed about the program's purpose, procedures, possible benefits and risks.
- You have been given the chance to ask questions before you sign.

- You have voluntarily agreed to be in this program

Print name of Adult Participant	Signature of Adult Participant	Date
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Print name of Person Obtaining	Signature of Person Obtaining Consent	Date
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Consent



Ask the participant to mark a “left thumb impression” in this box if the participant (or participant’s parent) is unable to provide a signature above.

Appendix 2 Consent form for participation in research

(By interview,)

Investigating Lived experiences of Community Home-Based Palliative Care volunteers in Ndola district.

I

Hereby consent to participate as requested in the research study of investigating lived experiences of Community Home-Based Palliative Care volunteers in Ndola district.

I have read the information provided.

The details of procedures and any risks have been explained to my satisfaction.

I agree to answer questions for the questionnaire during my participation

I am aware that I can retain a copy of the Information Sheet and Consent Form for future reference.

I understand that:

- I may not directly benefit from taking part in this research.
 - I am free to withdraw from the study at any time and I am free to decline to answer particular questions.
 - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
 - Whether I participate or not, or withdraw after participating, I will have no effect on any treatment or service that is being provided to me.
 - Whether I participate or not, or withdraw after participating, I will have no effect on my livelihood as pertains to caregiving.
 - I may ask that the observation to be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.
6. I agree/do not agree that the information recorded on the questionnaire being made available to other researchers who are not members of this research team, but who are

judged by the research team to be doing related research, on condition that my identity is not revealed.

7. I have had the opportunity to discuss taking part in this research with a family member or friend.

Participant's signature.....Date.....

Who do you call if you have questions or problems?

Call me, Catherine Katentemuna Musonda

Cell no 09774888045 or 0950454189 Email: musondachaile@yahoo.com

Call or contact the University of Zambia Biomedical Research Ethics Committee office for any ethical concerns. The Ethics Committee contact information is:

Address: The Chairperson of the Biomedical Research Ethics Committee, University of Zambia, School of Medicine, Ridgeway Campus, P.O. Box 50110, Lusaka.

Telephone: 260-1-25606 Fax: 250753 E-mail: unzarec@zamtel.zm

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name

Researcher's signature.....Date.....

NB: Two signed copies should be obtained. The copy retained by the researcher may then be used for authorisation of Items 8 and 9, as appropriate.

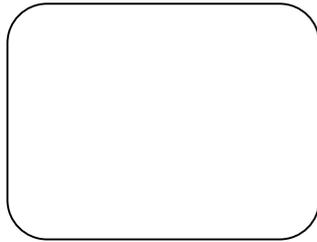
8. I the participant whose signature appears below, have read a transcript of my participation and agree to its use by the researcher as explained.

Participant's signature.....Date.....

9. I, the participant whose signature appears below, have read the researcher's report and agree to the publication of my information as reported.

Participant's signature.....Date.....

Thumb Print



Appendix 3 Questionnaire Guide

IN-DEPTH INTERVIEW GUIDE FOR HOME-BASED PALLIATIVE CAREGIVERS (HBPCs)

Topic: Investigating lived experiences of HBPCs in Ndola district.

Date of Interview:

Place of Interview:

Interview Number:

INSTRUCTIONS (Read and understand carefully)

- ❖ Before the interview commences, allow the respondents to understand information provided on the participant information sheet thoroughly, and when agreeable, make them sign the consent form provided.
- ❖ Commence the interview with questions in this guide in a more probing sense to allow them give responses with adequate explanations.
- ❖ Do not rush the respondents into answering and do not lead them into responses they could have not thought of, but give them time to express themselves independently and at length.
- ❖ Pose emerging open-ended questions as follow-up questions to particular responses and not line-listing questions as they may limit responses.
- ❖ Inform them that whatever responses they will give, opinions they will express will be considered with utmost respect.

English interview guide

SECTION	DISCUSSION	SUMMARY NOTES
A	OBJECTIVES	
General objective To investigate lived experiences of Home-based palliative caregivers in Ndola		

Specific objectives		
1. To describe resource support services for HBP caregivers in Ndola.		
2. To explore personal psychological experiences of HBP caregivers in Ndola.		
3. To determine the opportunities HBP caregivers in Ndola realize from HBPC practice.		
4. To establish the challenges HBP caregivers encounter during caregiving processes.		
B	WORK RELATED INFORMATION	
1.Duration of community work service:		
2.General experience:		
3.Trainings and orientations undergone:		
C	INTERVIEW GUIDE	
QUESTIONS	PREDETERMINED THEMES	
1. What kind of support have you been receiving when caring for the patients with long term illnesses like cancer, HIV/AIDs, stroke in your community?	<i>Resource support experiences:</i> Health information (education, mentorship & supervision);	

	<p>Materials (stationary, income generating tools etc);</p> <p>Money (allowances, transport money).</p> <p>Manpower (Families, friends, professionals etc)</p>	
<p>2. How have you been feeling when carrying out caring activities for patients with life-limiting illnesses?</p>	<p><i>Psychological experiences:</i></p> <p>Emotional & Mental stress; Stigma; Depression;& Social exclusion etc.</p>	
<p>3.What do you think are the things that you can explain as benefits you gain in the palliative care programs?</p>	<p><i>Opportunities experienced:</i></p> <p>Rewards; employment; social status; recognition etc.</p>	
<p>4. Explain the problems that you have been facing in the process of caring for the chronically ill patients in your community?</p>	<p><i>Challenging experiences:</i></p> <p>Work overload; physical burnouts; networks;& Caregivers' competing priorities and task shifting etc.</p>	
<p>5. How would you want the program of home-based palliative caregiving to be improved?</p>	<p><i>Recommendations</i></p>	

Appendix 4 Translated participant information sheet, consent form and questionnaire guide in Ichibemba version.

ichipepala cha kukonka ba kasalwa bakwasuka amepusho yakufwailisha

Apa ku belengela 8.0

Isukulu likalamba muno Zambia, (University of Zambia) ilya chiputulwa ca bumi bwa chintu bwingi.

Umulandu wa masambililo: ukufwailisha pa mibombele nefyo bapitamo ku baipelesha ukubombela mu kusunga no ku pempula abalwele ba malwele ya ntanda bwanga abekala mu mayanda (home based palliative care volunteers)

Ishina lya musambi ya milimo ya kufwailisha ni: Catherine Katentemuna Musonda,

inambala yapa sukulu (UnzaBrec no.):

Umulandu wa mulimo wa kufwailisha atemwa ukuchecheta

Aya amasambililo ya kuchecheta atemwa ukufwailisha ayo indecita ya kungafwa ukupelwa ichitupa cikalamba icha masambililo ichiitwa master's degree , palwa ku tungilila ubumi bwakutangata ichintu bwingi muno calo, icho ndechitila pa University of Zambia , pe sukulu lya muti ,ilya pa ncende iyitwa Ridgeway Campus mu musumba wa Lusaka.

Pakubomba bwino uyu umulimo ne fishinka fikafume , indekabila sana ukumfwikisha no kumona imilimo no bumi bwa milimo yaba katungulula abaipelelwe abene ukubombela abantu mu milimo yabumi (volunteers) bapitamo cila nshita – lintu baleteensha no kusunga abalwele ba malwele ya ntanda bwanga (aya kokola pa kupola) mumayanda.

Ilyo nkapwisha ukubomba uyu umulimo wa kufwailikisha ,muli no kwebwa pa fikatumbukamo no kusumina no kunsuminisha kwenu ku kalenga ifikafumamo fikasalanganishiwe na munchende shamilimo ya kalamba mu ciputulwa ca bumi elyo nakubekala calo pakutula ifisabo fyaici icifwaila fya bomba umulimo wakulundulula mukuwamya ubumi bwa bekala mishi pamo ne calo conse.

Eico, nsuminsheni uku mwipushako amepusho ayanono ,kabili aya yanguka ayakuminefye imilimo mu bomba kabili iyo mwaishibisha.

Bushe mulandu nshi walenga ukuti mubulemo ulubali no kuisansha muli uku kufwailikisha?

Indechetekela nokusubila ukwipusha bakaipela wakusunga no kutensha abalwele (homebased caregivers) pa nshita iyitali aba mu musumba wa ndola. mwebasalilwe muli ikumi limo na babili (12) ukubomba mu mulimo wa cifwaila pantu mwalisangwa namukwata imibele ne filekabilwa muli uyu mulandu.

Inshila shakukonka

Inga mwasumina ukubomba naine uyu mulimo wakuchegeta , indekabila tusuminishanye nenu mumusango wakushilishita (ukusainishanya) ipepala lya cipangano ca kusumina, icakulanga ukuti na musumina. Panuma tuli nokwikala nenu pa ncende ifwe bonse twingatemwa , pa nsa yaba mineti amakumi yabili(20) nangula amakumi yatatu (30) nokulanda pafyo tubomba. indinokumwipusha amepusho ukubomfya ipepala elyo no kubika amasuko yenu (record) mukasolobelo akanono akapala akalimba (recorder) pakuti ca njafwako ukwibukisha fyonse ifyo twakulalanshanya nganakaasha.

Ingacakuti ukukopola amashiwi yenu muli aka kalimba (record) ca mukosela , ninshi kuti nalalembafye fyonse pe pepala nangu cingatuposela inshita. Ilyashi mwakulampela indi nokulalamba elyo panuma, ukutaipa no kupangamo icitabo icakuti cabelengekwa no kumfwika bwino ku bantu. Icho mushifwile kusakamana cakuti amashina yenu tayakalumbulwemo nangu pamo. Muli uku ukulanshanya indi nokumwipusha amepusho pa milandu iyi:

Bushe bwafwilisho bwa shani mupoka ku bekala calo abo cikumine mu kumutungilila mu kubomba imilimo ya kutensha abalwele abakokola na malwele yabo mu ncende mu bombela?

Indesubila ukusambilila kuli imwe ifyo mufikilisha umulimo wenu uwakutangata abalwele , maka-maka balya abesa mukufwaya ukuya tangatwa na bambi bakafwa nangu ku fipatala fimbi.

Nakabili kuti natemwisha mwanondolwelako amafya mushinwananakabili kuti natemwisha mwanondolwelako amafya mushinwananakabili kuti natemwisha mwanondolwelako amafya mushinwana nayo ilyo mulesakamana abalwele.

Cimbi kuti natemwa ukumfwa kuli imwe ifyo mwingatemwa imilimo ya home- based palliative care inga waminishiwa , mukulumbula ifintu mwingatemwa fycitwa nangu ukufumishwamo.

Napakulekelesha, kuti natemwa ukumfwa ukufuma kuli imwe ubusuma abalwele bashingwana na malwele ya ntanda-bwanga elyo na bekala calo basanga mu milimo mubomba iya kutensha abalwele mumayanda munchende mwikalilalmo (home- based palliative care) inga abantu abaipeleshafye ukusakamana ubumi bwa bantu.

Amasakamiko elyo ne fishingomfwika bwino

Tamuli no kupita mu fintu ifyayafya sana mukubomba naine muli uyu umulimo ; lelo limbi mukwibukisha imilimo ya kunuma intu mwapitilemo mukutensha abalwalishe , limbi kuti mwaumfwa ububi icakuti teti mutemwe no kulandapo. Lelo mufwile mwaishiba ukuti limo- limo inkalaipusha amepusho ayakuti ya mufisha ku mikoshi. Nechi temulandu wakufwaisha uku mumfwisha ububi, lelo ni mukufwaya ubwafwilisho bwa kwasuko busuma ubwingesa yafwa abapanga ifyebo (policies) ifya milimo pa kucingilila ubwafya bumo – bwine ukucitika ku ntanshi. Nakabili indemulaya ukutila techonse ico mukalanda muli uku kulanshanya cikasalanganishiwa kuli onse.

Ubukumu nangu ubunonshi

Kuti chawama mwaumfwa ukuti uku ku checheta atemwa ukufwailisha takubeleleko mukusekesha abaleyasuka nangu abaibimbilemo ; lelo ukwasha ukufushishako amano ayakumwafwilisha mukwishibisha ifingi ifikumine ku kusakamana abalwele abasangwa mu mishi mu bombela nokwafwa ukupakamisha imilandu ya bumi.

Kulubali lumbi , uyu mulimo kuti wayafwilisha mukupekanya no kutantika bwino umulimo wa ku salanganya aba bomfi , umuti ne fibombelo pa ku bomba bwino imilimo ya buumi elyo no kucefya akapatulula akabako ku milimo ya buumi mu mishi yesu ilyo aba bomfi bashipokelela ilyashi no tusebo utwakubafwa.

Amalipilo

Ukubulamo ulubali muli uyu mulimo takuli amalipilo ayali yonse (allowance). akandalama kalimofye ku mubwesha iyo muposele mukwendela epela (transport refund).

Ukusunga inkama yamashiwi yakafuma mukuchecheta pakufwailisha.

Apo natwishiba ukuti fyonse ifikafuma kuli imwe fikasungilwa munkama, chili nokusendwa ifyo fine mukukana lemba nangu fimo pali imwe ifyaakumusikolola inkesha nokusunga amapepala bwino nokukomenwa mumbokoshi. Fyonse fili noku chingililwa bwino pa myaka ibili mukulolela inshita elyo panuma fikesaonaulwa.

Bushe kuti caba shani ingamulefwaya ukuibimbamo mukufwailisha?

Ukusala kwenu. takuli nangu umo uwinga mu patikisha ukuba umo paba kalaipushiwa amaepusho muli uku kuchecheta. Inga mwaatemwa ukuleka libe ninshi na mwamba imilimo; nalyo line takuli ukuba ubwafya nangu bumo, muli bantungwa ukuleka apabula nowakumisokonsha nakalya.

Ninani muli nokuyako ilyo mwakwata ubwafya nangu ichakuilishanyapo?

Ntumineni ine: Catherine Katentemuna Musonda, pali kamusange kandi 09774888045 nangu 0950454189

email; musondachaile@yahoo.com

Nangu kuti mwatumina kuli ba University of Biomedical Research Ethics Committee office, nokwipusha pafikumine amafunde ne mibele. Apakubasangila niapa, bakangalila ba biomedical research ethics committee, University of Zambia, School of Medicine, Ridge way campus, P.O Box 50110, Lusaka.

Lamy :260-1-25606

Fax: 250753 email: unzarec@zamtel.zm .

Bushe ukufwatika (ukubika signature) pepepala lya kusuminishanya cilepilibula cinshi?

Ukushilishita (ukusaina) pacipepala cilepilibula:- namwebwa umulolele imilimo, ifyakukonka, ubusuma bulimo elyo namalangulushi.

Namupelwa ishuko nensambu sha kwipusha lintu tamulashilishita (ukusaina)

Namuisuminina ukubomba muli uyu mulimo mukufwaya kwenu.

Ishina lyabakalamba baleibimbamo
Inshiku

Ukushilishita

Ishina lya ulepokelela

Ukushilishita

InshikuNgatabaishiba ukusaina- kuti bafwatika ukubomfya icikumo ca kukuso

Appendix 5 Icipepala cakusumininapo ukubomba umulimo waku checheta atemwa ukufwailisha
(Consent Form)

Ukuwafwailisha pa buumi bwabekashi abaipelesha ukusunga nokutensha abalwele ba malwele ya ntandabwanga pa mayanda mu Ndola district

Ine

.....
.....

Nasumina ukuisansha muli uku ukubomba mu mulimo wakufwailisha pamilimo yakusunga ifyo abekashi ba ipelesha abene muku tangata abalwele bamumayanda abamu Ndola district bapitamo.

Nimbelenga na fyonse ifilembelwe nokupelwa.

Ifishinka fyonse ifyakukonka ifipelewe fyonse nafilondololwa bwino nokumfwa ningumfwa, nasumina ukwasuka nokuisansha muli uku ukfwailisha nokupela amasuko kumepusho yakapelwa.

Ndi uwailuka kaili ninjishiba ukuti mfwile nasungako ifipepapala fimo ifya kusuminishanya pakuti kuntanshi wakwata icakusontapo lintu kwaba ukufwaye cho.

Ningumfwa kaili ninjishiba nokuti:-

Nshakamonemo ichili chonse mukulungatika mukuisansha muli uyu mulimo

Indi umu ntungwa ukupelesha uyu umulimo pakati elyo nokukana yasuka amepusho yamo.

Elyo ilyashi nangula lysaendwa pafyo inkasuka , ifikasabankanishiwa kubengi, ngefyo chisolwe nshakeshibikwe, pantu ifyakunji shibilako tafyakasokolowe fikaba fya munkama

Nangu inkaibikemo nangu ukukanaibikamo, atemwa ukupelesha pakati, fyonse tafyakabe no bwafya ubuli bonse-ku kundapwa ne milimo yamikalile yandi.

Kuti nalomba ukuleka ukubomba pamulimo umo inshita iyili yonse ukwabula ukufulunganya ukufwailisha.

Nasuminisha/ nakana ukuti amasuko yonse ku mepusho yapelwe mwipepala ili pakufwailisha yapelewe nakwibumba limbi nalyo ililefwailikisha cikulu fye ine nshishibikwe.

Nalikwata ishuko lyakulanda pakuti nintemwa ukubomba mu mulimo wa kufwailisha, nalandile nolupwa ne chibusa

Ukushilishita kwa kafwa.....

Ubushiku.....

Nasumina ukuti ni nondolola umulolele umulimo wa kufwailisha kuli bakafwa elyo ni nsubila nokutila no kumfwa nabomfwa .

Ishina-----

Ikushilishita ----- Ubushiku.....

Uluchebu: ama pepala yabili ayashilishitiwa yasungwe. umwine wakukondenkanya umulimo abule po limo ilyakumupelelapo amaka yaku checheta, ayalipacikomo calenga chine konse konse (8) elyo nechalenga pabula (9) ukulingana nefyo fyatantikwa.

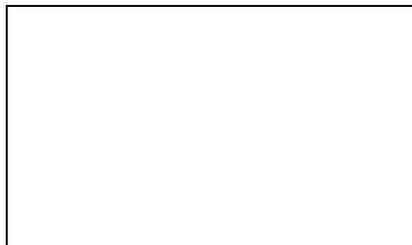
Ine newasangilwe muli uyu mulimo ne wa shilishite pali ili pepala, ninsoma ifilembelwe nokusuminisha ukuibimbamo muli uku kuchecheta ukulondolwelwe.

Ukushilishita kwandi..... Ubushiku.....

Ine neo ukushilishita kwandi ilipesamba, ni nsoma akasebo (report) nokusuminisha ukusabankanya iyi report.

Ukushilishita kwandi..... Ubushiku.....

Apa kufwatika ichikumo



Appendix 6 Ifya kukonka pa kwipusha amepusho (questionnaire guide)

Ichipande	Ukulanshanya	Ifikankala ifilefumamo
A (Ichalenga bumo)	Imilimo	
Ipange likalamba ukufwailisha pamilimo intu abasunga abalwele pa mayanda babomba nefyo bapitamo mumusumba wa ndola		
<p>Amapange ya fishinte</p> <p>1. Ukulondolola ubwafwilisho ubwapusana pusana ubu kumine incenshi sha mano, ifipefyakubomfya , indalama atemwa utunyampuku utupelwa kuli bakasunga naba katensha wabantu abalwala nshita ntali mumayanda.</p> <p>2. Ukufwailikisha pabuumi bakafwa aba bapitamo mumatontonkanyo ilyo bale afwilisha ababalwele bapa mayanda’</p> <p>3. Ukufwailisha amashuko atemwa ubukumu bakatensha aba abaipelesha ukutensha abalwele ba ntanda bwanga bamwenamo</p> <p>4. Ukuchecheta amafya bamuninefwe aba bashingwana nayo mukutensha abalwele bantandabwanga.</p>		
B (Ichipande chalenga bubili)	Fimbi ifilekabilwa ukwishiba pali iyi milimo	
1. Inshita ipooswa ukubomba imilimo mumushi mukusunga abalwele		
2. Fimbi ifyo mupitamo ilyo mulebomba ifyapusana pusana		
3 Amasambilo mu pelwa no		

kukanshiwa uko mupitamo		
C (Ichipande chalenga butatu)	Ifikomo fyakukonka pa kwipusha amepusho	
Ampusho	Ifikomo fimo ifyakuloleshapo	
1. Bushe bwafwilisho bwa musango washani mu poka ilyo mulesunga abalwele ba malwele yantanda bwanga (cancer, hiv/aids na stroke)?	Ubwafwilisho bapokapo:- ifipe fyakubomfya (ifisolobelo, amafundisho yapa bumi, amapepala,--) ulupiya (transport allowance)	
2. Mumfwa shani ku mutima ilyo muletangata abalwele abo amalwele yafisha nakumfwa?	Mumatontonkanyo ukulingana namano yabo, imutima, icikonko ukukuntikilwa.	
3. Mukuchimona kwenu, bushe busumanshi no bunonshi bwaba mukusakamana abalwele?	Ubukumu bwaba mukutensha:- ifilambu , incito , umucinshi no kwishibikwa .	
4. Londololeni amafya mupitamo ilyo mulesunga noku tangata abalwele ba malwele ya mutatakuya munchende mwikalilamo?	Amafya mupitamo imilimo ubwingi icifukushi ,icikonko, ukucimfyanya mukupwisha imilimo	
5. Bushe imilimo ya kutensha kuti yatwalwa shani pantanshi?	Ukulanda mulibumpandamano	

Appendix 7 Interview Context (To be completed by the interviewer)

ID of interviewee:

Name of Interviewer:

Date of the interview:

Start-time:End-time:.....

Facility name for the interviewee:

Brief description of the interviewee

.....

Brief description of the facility

.....

Interview Venue (name and description of the environment)

.....

Respondents' level of participation

.....

Interest-level:

.....

Any adverse event (if any in what form and how was it handled?)

.....

Respondents' absolute interest in the discussion

.....

Any other information.....