

Department of Global Public Health and Primary Care

Centre for International Health

University of Bergen, Norway



Palliative care services at Nkhoma, rural Malawi – A qualitative exploration of experiences of the care providers and the recipients

Adeosun Olawale Adedapo MD

Palliative care services at Nkhoma, rural Malawi – A qualitative exploration of experiences of the care providers and the recipients

ADEOSUN OLAWALE ADEDAPO

This thesis is submitted in partial fulfilment of the requirements for the degree of Master of Philosophy in Global Health at the University of Bergen

Centre for International Health
Department of Global Public Health and Primary care
Faculty of Medicine and Dentistry University of Bergen, Norway 2020

Supervisors

Kaern Marie Moland

Professor, Centre for International Health
Department of Global Public Health and Primary Care

Astrid Blystad

Professor, Center for International Health
Department of Global Health and Social Medicine

Abstract

Background and purpose

Palliative care is rapidly developing in Africa, but still many people live and die in pain because the coverage and the capacity to meet the needs are low. Morphine is a potent opioid pain killer, however its circulation in low-income countries is extremely limited (0.03%). Almost all the available morphine is consumed in developed countries. This research is part of a master study in Global Health performed at the University of Bergen in Norway, in collaborations with institutions in Norway and Malawi, on provision of palliative care within Nkhoma hospital catchment area. The aim of the research is to investigate the strengths and limitations associated with provision of palliative care in the low income setting of Nkhoma Malawi, as experienced by both the palliative care providers and care recipients. It aimed to describe practice models, strategies and challenges to delivering end-of-life care and to create awareness and provide knowledge that can be used to further strengthen the palliative care program at Nkhoma, Malawi and other similar settings.

Methodology

A qualitative research design was used and purposive selection of participants was done to ensure diversity of participants. To boost the comprehensiveness of the report, data was triangulated primarily from four sources, namely: clinic documentations, active participatory observation and participants observation, in-depth interviews with palliative care recipients as well as with the palliative care providers, both within the hospital premises and in the homes of care recipients. In addition, discussions during meetings and informal chats, provided substantial insights into the delivery of palliative care services at Nkhoma. The participants included patients and their guardians, as well as healthcare providers, chaplaincy and community volunteers. Twenty (20) participants took part directly in the interviews that were conducted in English or in Chichewa with the help of a research assistant. The interviews lasted about 45 to 60 minutes and were audio-recorded after obtaining consent. In addition, more than thirty (30) patients were observed in the course of treatment, as part of the observatory

component of my data collection, whose focus was to collect information on interactions, daily routines, practices, challenges and follow ups. Recorded interviews were thereafter transcribed verbatim and translated where applicable, followed by a four-step Malterud's systematic text condensation which is a descriptive and explorative method for thematic cross-case analysis. Ethical approval was obtained ahead of the research from authorities in Norway and Malawi.

Findings

The study shows that many patients diagnosed with chronic life-limiting/threatening illnesses struggle with pain and other physical symptoms, such as stigmatization, and recurrent vaginal bleeding in patients with cervical cancer. As a result of these symptoms, many patients are unable to work and provide for themselves and their family. This leads to severe poverty and complete dependence. Moreover, poor access to resources and medication is a challenge that many face, since the community health centres, that are closer to the patients in those rural area, do not provide palliative care services due to drug policies restricting opioid pain killer distribution to the health centres.

In addition to hospital-based care model, the Nkhoma palliative care team provides home-based services, which involves travelling far into the rural communities to provide physical, psychosocial, and spiritual care. However, the team is often unable to keep up with its home-based care schedule, due to limited resources and money to fuel the ambulance. Thus, many patients in the rural areas still live and die in pain. While the team may be able to address some of the physical symptoms, available resources significantly limit what they can do to meet the psychosocial and socioeconomic needs of patients.

Conclusion

Findings show that drug policy and availability, training, and financing are among the multiple and interconnected challenges affecting palliative care services at Nkhoma. Patients with chronic life-limiting illnesses and poverty, are especially prone to psychosocial and spiritual distress which contributes significantly to the total pain. In line with the palliative care holistic approach, serious attention should be giving to psychological, socioeconomic, and spiritual distress, as well as improved access to opioid pain-relief medications at centres closer to patients.

Table of Contents

Abstract	4
Table of Contents.....	6
Glossary of acronyms.....	8
Acknowledgement	9
Introduction and Background	10
The global burden of serious health-related suffering (SHS).....	10
Palliative care policies, Universal health coverage and Human rights	11
Palliative care and Access to Morphine in Africa.....	12
Palliative care in Malawi	15
Palliative care – historical roots and current concept	17
Relationship between palliative care and curative treatment	20
Diseases requiring palliative care.....	21
Models of palliative care services	21
Justification	24
Aims and Objectives.....	25
Methodology	26
Study Design.....	26
Study Setting	26
Study participants	28
Recruitment of participants	28
Inclusion and Exclusion criteria.....	29
Methods of data collection	30
Qualitative data analysis	33
Ethical considerations	35
Harm or Benefit	35
Findings	37
A life of pain and suffering	38
<i>“I am more like a small child now”</i>	38
<i>“I feel a lot of pain and...I don’t find peace at all”</i>	41
<i>“I don’t play... because I feel too weak”</i>	43
<i>“I wish to start worshipping again”</i>	45
Palliative care at Nkhoma	47

The providers and their roles	48
Common cases requiring palliative care at Nkhoma hospital	51
Organization of Nkhoma palliative care services	53
Comprehensive palliative care - Nkhoma holistic approach	54
“They come with little physical pain but huge psychological and social pains”	54
The Hospital-based care.....	57
How are follow ups done?	63
The Home-based care	64
Establishing Community-based palliative care.....	69
Funding for the palliative care services at Nkhoma	71
Gaps and barriers of the Nkhoma palliative care program	73
Tensions and latent conflicts within the team	73
Drug policy affecting palliative care	76
Financial, Psychological and social barriers.....	77
Training – “in school we don’t learn much about morphine”	79
Is false hope to patients the answer?	81
Discussion	82
Understanding the pain and suffering of patients.....	83
Bridging palliative care access gaps through drug policy, training and research	85
Methodological strength and challenges in the palliative care research	88
Conclusion	92
Recommendations	93
Appendices	95
1. Information Sheet and Consent Form (English)	95
2. Information sheet and Consent Form (Chichewa)	97
3. Interview Guide.....	99
4. Participatory observation Guide.....	101
5. Letter from Haraldsplass hospital.....	102
6. Letter from Nkhoma Hospital	103
7. Ethical approval Malawi.....	104
8. Ethical approval Norway	105
9. Ethical approval Norway (Norwegian).....	106
References	107

Glossary of acronyms

SHS	Severe Health-related Suffering
WPCA	World Palliative Care Alliance
WHO	World Health Organization
CHC	Community Health Centre
UHC	Universal Health Coverage
APCA	African Palliative Care Association
PACAM	Palliative Care Association of Malawi
NMH	Nkhoma Mission Hospital

Keywords: Palliative care, Morphine, Nkhoma, Malawi, Physical care, Psychosocial care, Spiritual wellbeing, Global health, Universal Health Coverage.

Acknowledgement

It started with a favourable response from the Global health admission committee. To them, as well as all the staff at Centre for International Health (CIH) University of Bergen, under the leadership of Prof. Bente Moen, I say a big thank you for building me up as a researcher and an academic. Special appreciation goes to my supervisors Prof. Karen Marie Moland and Prof. Astrid Blystad. You showed me both the thick and thin of qualitative research, brought out the objectivity in qualitative research and the treasure in subjectivity. You compassionately and guided me through, from proposal development till thesis submission. You are wonderful!

I am grateful to the Haralds plass Hospital team, who have made my trip to Malawi possible. Thank you Prof. Jan Henrik Rosland and Aina Theressa for every support you provided. You prepared the ground for my fieldwork, and your positivity urged me on even after the fieldwork. In addition, I appreciate the Medical director at Nkhoma Hospital, as well as the coordinator of the palliative care program Mrs Ellen Chizimba, who together with Mr Sam Kabota and every member of team have made my research a success, thank you all for the farewell party and the gift. I cannot forget my research assistant and my friend – Alice Mazengera, you are such a nice and efficient person, thank you.

Thank you Prof. Thorkild Tylleskar for our first course, it made an excellent first impression. Linda Karin Forshaw, is always eager and able to assist, we love you and it was my pleasure to work with you as a student representative. Elinor Bartle, you have been encouraging and have showed us the value of professionalism in presentations. Moreover, I cannot forget my experience in Zambia, thank you Prof. Ingvild Fossgard for the opportunity, and Prof. and Mrs Michello of University of Zambia, School of Public Health for being there for us. I appreciate my wonderful colleagues and friends, the 2018 batch at CIH. And for my friends far away, who remain close despite the distance, – the family of Temitope Bakare & Prudence M. I appreciate your company.

Futhermore, I appreciate Mr & Mrs Benjamin Phiri, Mr & Mrs Lenon Nkunguru, Mr & Mrs Matewe as well as Andrew and Co, you showed me the beauty of Malawi and together we made our way to the towering Nkhoma mountain, gazed at the beautiful lanscape while descended at dusk. Together we travelled Monkey bay, camped at Mangochi, and swam in Lake Malawi.

My family has always been there for me, and together we have done this. You are my world and my everything. Thank you is not enough to appreciate my parents Mr and Mrs J.O Adeosun, and my sister and her family – Mr and Mrs Adigwe. I love you and miss you.

Above all, all the praise and glory goes to Jehovah God, – the giver of life. Soon *“he will wipe out every tear ... and death will be no more, neither will mourning nor outcry nor pain be anymore”* – Revelation 21:3, 4. So, I look forward to that time when *“no resident will say ‘I am sick’”*.

Introduction and Background

The global burden of serious health-related suffering (SHS)

Globally, every year more than 20 million people have been estimated to need palliative care towards the end of their lives and over two thirds are elderly people (Connor et al., 2014). For instance, in 2011 almost 30million people died from diseases requiring palliative care. In 2015, more than 61 million people experienced Severe Health-related Suffering (SHS) and this included about 25 million , which is almost half of the 56.2 million deaths reported globally. Yearly, patients with life-limiting or life-threatening illnesses accrue no less than 6 billion symptom days (Knaul et al., 2018).

Based on data from the World Health Organization (WHO Global Health Estimates) two thirds of the nearly 55 million deaths, that occurred worldwide were due to noncommunicable diseases, whereas communicable, maternal, perinatal and nutritional deaths account for 25%, while the remaining 9% are as a result of injuries. Not all dying patients will need palliative care, according to the report, an estimated 37.4% of total mortality, that is deaths from all causes, need palliative care (Connor et al., 2014).

Level of development of palliative care vary from country to country, while some are classified as having an advanced integration of palliative care into their health system, others have no identified palliative care services. Global levels of palliative care development were mapped by the Worldwide Palliative Care Alliance, in the report 234 countries were categorized into groups. There were 75 countries (32%) in group 1, where no known hospice-palliative care activity was found. Group 2 countries are those at the level of capacity building, 23 countries are in this category, this constitutes about 10% of countries. The third group is subdivided into subcategories. Group 3a consisting of 74 countries (31.6%) have isolated palliative care services, while the 17 (7.3%) countries in Group 3b have generalised provision of services. Group 4a consist of 25 countries (10.7%) with preliminary integration of hospice-palliative care services into their mainstream service provision, while the remaining 20 countries (8.6%) that already

have an advanced integration of hospice-palliative care services were classified as Group 4b according to the Global Atlas of Palliative Care. (Connor et al., 2014)

Palliative care policies, Universal health coverage and Human rights

The World Health Assembly made a landmark global resolution (resolution WHA67.19) on palliative care policies in 2014, where the WHO and member states were called on to improve access to palliative care as a core component of healthcare systems emphasizing care at primary and community/home-based levels. Universal health coverage (UHC) cannot be achieved without adequate attention to palliative care and pain relief (World Health Organization, 2014). Other essential components of health care have received much attention unlike palliative care, and the need for pain relief even for the most vulnerable population is enormous.

WHO definition of Universal health coverage demands that all have access to the promotive, preventive, curative, rehabilitative, and *palliative health services* they need, of sufficient quality to be effective, while ensuring the services do not paralyze patients financially. Countries in the World Health Assembly (WHA) in May 2014, took a resolution (67.19.42) to achieve UHC by integrating palliative care into their health system and urged the WHO to champion this. (World Health Organization, 2014).

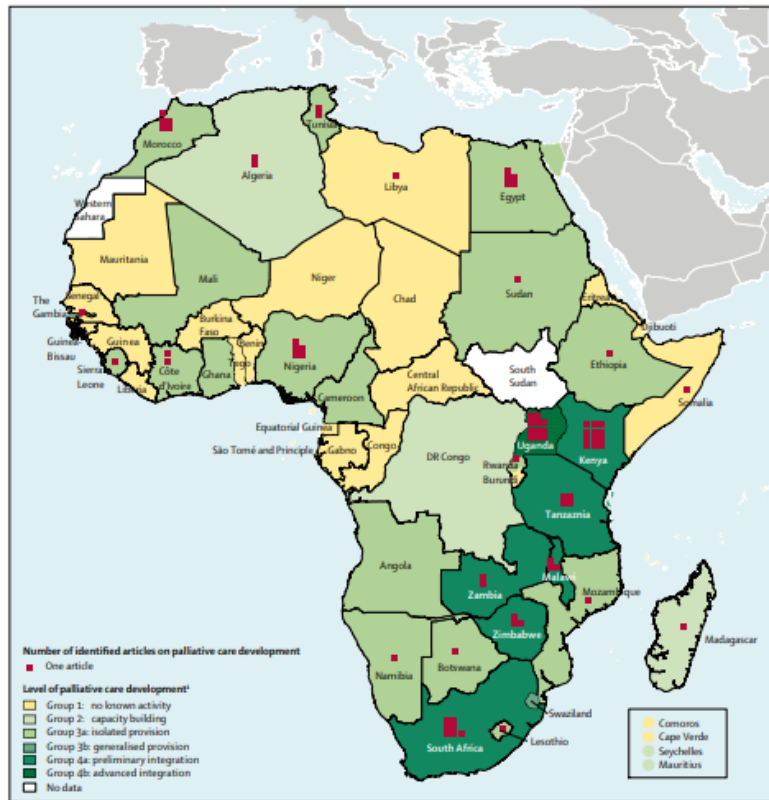
The international human rights to health calls for the “right of everyone to enjoy the highest attainable standard of physical and mental health” ((ICESCR) Article 12.1, 1996). Though not enforceable, it is expected that countries will align themselves to ensure that the rights are upheld. The United Nations have called denial of access to pain relief is inhumane and degrading treatment. Thus, the implementation of palliative care into health system has been advocated by WHO, and other intergovernmental and Non-governmental organizations such as World Palliative Care Alliance, Human Rights Watch (Human Rights Watch, n.d.) (The Korea Declaration, 2005) European Committee of Ministers (Council of Europe, 2003) and many more organizations on all continents (Connor et al., 2014)

It was on the basis of these and others that Brennan argued that palliative care is a basic human right and denying access is tantamount to infringement of individual right. (Brennan, 2007). Despite the definition showing palliative care as a central component of universal health coverage, most countries are yet to integrate it into their health system. This implies that no UHC can be achieved without at least the minimum palliative care service package A Lancet Commission noted that countries cannot achieve Target 3.8 of the sustainable development goal (SDG) before 2030, without integrating palliative and pain relief into the system, thus ensuring universal access as well as eliminating the impoverishing effect such services may cause to the poor (Knaul et al., 2018), this is particularly important in low-middle-income countries where the Essential Package should be expanded to include opioid analgesics – morphine, radiotherapy, chemotherapy, and palliative care.

Palliative care and Access to Morphine in Africa

Nearly eight of ten (78%) adults that require palliative care at the end of life belong to low-middle-income countries and the vast majority (98%) of children that require palliative care services at the end of life live in low-middle-income countries while 83% of those are in the low-income countries. Several studies have described levels of palliative care around the world and in Africa. (Lynch et al., 2013) (*Quality of Death Index*, 2015) Uganda is listed in the highest level (4b: advanced integration), whereas Malawi, along with Tanzania, Zambia, and Zimbabwe are listed in the phase of preliminary integration level (Rhee et al., 2017). Countries income has been shown to indirectly correlate with need for palliative care, with high income countries having the least needs while low income countries have the highest needs (Connor et al., 2014). Preventable diseases and health conditions account for the vast majority of the over 20 million deaths associated with SHS in low-middle income countries (LMIC). The leading diseases requiring palliative care in LMICs include cancer, diseases associated with HIV/AIDS, premature birth or birth trauma, tuberculosis, and malnutrition (Knaul et al., 2018).

Figure 1: The map below shows levels of Palliative Care development across African countries.



Sources: (Lynch et al., 2013) (Rhee et al., 2017).

In sub-Saharan Africa, about half a million people die of cancer every year. Even though there is increased adoption of policies in favour of palliative care, many do not have access to the care. Efforts are being made to integrate palliative care into health systems. However, poor availability and access to health services remain a major barrier resulting in no or delayed presentation to the hospital, as a result about 80% of cancer cases diagnosed in Africa are an advanced and incurable stage requiring palliative care as the mainstay management. Malignancies associated with HIV are common, it was also found that the lifetime risk of a woman in Africa dying of cancer is double that of women in developed countries (R. Harding et al., 2013). Studies done in five African countries reported the multi-dimensional nature of suffering in patients namely physical, psychological, social, and spiritual problems, and this highlights the need for an inclusive palliative care service (Sepulveda et al., 2003). Qualitative studies have shown that

patients in Africa, prioritized spiritual wellbeing over physical dimensions of quality of life. (Selman et al., 2012). According to a study based in Kenya, physical pain and financial anxieties predominate lives of patients with cancer, further noting that appropriate pain killers, suitable food, essential medical-equipment, and care are usually inaccessible and/or unaffordable (Murray et al., 2003).

The need for palliative care is growing, especially for patient with incurable diseases. It has been estimated that African countries will account for over a million cases of cancer per year that cannot be cured (*London_Declaration_on_Cancer_Control_in_Africa*, 2007) . Conversely, only 3.6% of the available opioid pain killer are distributed to LMIC and only 0.03% is distributed to low-income countries. Annually, about 300 metric tons of the opioid analgesic- morphine are distributed worldwide, of these only a tiny fraction gets to LMIC, despite being the ones with the greatest need. For instance, developing countries account for over 80% of those who died because of severe health related suffering in 2015 and 99% of people living with HIV and cancer with untreated pain live in the developing world (Dix, 2012) . Studies have shown that low income countries receive only 0.1 metric tons, which is just 0.03%. This means that vulnerable people in poorer countries are living and dying in pain, which could have been alleviated with effective and inexpensive medication. This is considered not just a public health challenge but a ‘moral failing’ and perversion of fairness and justice (Knaul et al., 2018).

African Palliative Care Association provides the standard of quality palliative care across the continent and they recognize the need to ensure that the quality of care provided is acceptable just as measures are being taken to increase to service coverage. According to the WPCA, home based care services in Africa depends predominantly on volunteers. The African Palliative Care Association standards for quality palliative care service provision across Africa were developed by stakeholders across Africa and globally for target trainers and service providers involved with patients with life-threatening or life-limiting illnesses. The minimum standard requirements for palliative care centres varies, depending on whether the services are considered primary, which is the most basic care, secondary or tertiary which constitutes the most advanced care with specialist services (World Health Organization, 2016)

The last systematic review on the development of palliative care in Africa was carried out in 2017 by Rhee and colleagues. This comprehensive study of literature was a scoping review of peer-reviewed, published materials between 2005 to 2016 with articles on palliative-care development, for each African country. According to the study, palliative care services were concentrated in Kenya, South Africa, and Uganda, and 14 (26%) countries showed an increase in services during that timeframe. At that time Malawi had stand-alone palliative care policies unlike most other African countries with minimal to no identified palliative care development (Rhee et al., 2017), and has since scaled up its palliative care services through the joint efforts of Africa palliative care Association and foreign partners, bringing Malawi to level 4A – preliminary integration into the health system. Nigeria, for instance, is also said to be ‘making progress’ even though it has remained in the same Group 3a (isolated palliative care provision) since 2006 with only 7 palliative care centers in the whole country of 200 million inhabitants, with just 2 private and 5 government owned being run by only 5 formally qualified physicians and 4 formally qualified nurse specialist in the whole country. (Lynch et al., 2013)

Palliative care in Malawi

Malawi is one of the most resource poor countries in sub-Saharan Africa (SSA) and in the world, with an estimated 70.3% of the over 18million population living below the poverty line (UNDP, 2019). It is a densely populated country with low per capita health expenditure. Palliative care is developing in Malawi, with just 21 centres providing the care, this constitutes a small fraction of the over 600 public and non-governmental health facilities in the country (Government of Malawi Ministry of Health, 2011) (Ministry of Health of Malawi., 2004). The country is divided into three administrative regions, namely Northern, Central and Southern Regions. There are 28 districts: six in the Northern Region, nine in the Central Region and 13 in the Southern Region. The health care services follow the same system and are organized into three levels: primary, secondary and tertiary. Each region has its tertiary or central hospital (level 3) and each district

has a district hospital regarded as a secondary centre (level 2) within each district there are several health centres (Level 1) at primary level.

According to recent data from Malawi demographics, there is a huge disparity between urban and rural population distribution with an overwhelming majority dispersed in the rural area, with 17.2% urban population (*Malawi Demographics Profile*, 2019). More than seven out of ten people in Malawi are poor (UNDP, 2019), and over nine of ten people living in the rural area, with an overwhelming majority of rural households still poor (Zomba, Malawi: National Statistical Office., 2014). The poverty in Malawi is derived not only from poorly endowed households and communities, but also the result of significant reliance on risk-prone activities such as rain fed agriculture, which leads to fluctuations in incomes. Small households are especially affected because their primary source of income is the harvest and there are no insurances or order mechanism to cushion the effect of reduced harvest resulting from weather fluctuations. These seasonal changes have serious and significant impact on households.

Another main challenge in Malawi is the prevalence of HIV, about 12% of 15–49year olds in Malawi are infected with HIV, that means about one out of every ten people is infected, contributing to around 61,000 deaths per year attributable to AIDS. Besides the phycological and social pain that characterizes HIV infection from the moment of diagnosis, it is also associated with physical pain. Physical pain in HIV is associated with several factors, and often associated with superimposed diseases. More than 90% of those in need of palliative care and pain relief in Malawi do not have access to the needed care and medications (Felicia Marie, 2018).

The national policy on palliative care in Malawi was approved in 2014, and as a result many other policies has evolved, policies related to equity in access to pain medicines, capacity building, distribution of resources, patient and relatives involvement, organization and coordination. Trainings as well as research are also important issues to be addressed (Luyirika et al., 2016). In addition to the approval of care policy, efforts are being made to implement the components in the health system of Malawi. This involves several bodies such as the professional regulatory bodies, civil societies, the central medical stores, training facilities and institutions, as well as patients and their families. The policy makes provision for monitoring and evaluation for

palliative care activities across various regions in the country. According to reports, progress has been made such as the completion of care need estimation, established national reporting mechanism at the Ministry of Health, local morphine reconstitution into liquid version which is readily and easily stored and dispensed to patients and training of providers with over 300 trainers . The government is said to be covering up to 58% of palliative care needs in the country, while the remaining needs are covered by NGOs and other faith-based organizations (World Health Organization, 2016).

The little attention paid to palliative care until recently is reflected in the fact that between 1990 and 2007, the International Narcotics Control Board (INCB) received just one annual report on morphine use from Malawi. Subsequently, Morphine has been enlisted along with other high priority drug in the Essential Health Package Medicines and Supplies list. (Bates et al., 2008). Recently, palliative care has been proposed as a basic human right (Brennan, 2007), and now palliative care is recognized by the Ministry of Health in Malawi as part of a minimum standard of care for all tertiary institutions in the country (Tapsfield & Jane Bates, 2011).

Palliative care – historical roots and current concept

Palliative care has an ancient history, from the beginning humans have suffered chronic, life-limiting illnesses resulting in death. In 1887 for instance, Munk's treatise on easeful death was published, there he described comprehensive end of life supports including spiritual care (Clark, D., 2016). However modern history of palliative care began in the 1960s when doctors coined principles and practice of palliative medicine. At that time there was a growing concern about the process of dying, so it was easy to demonstrate the impotence of the new pain relief medications incorporated into the management of chronic and terminal illness.

At about this time some countries were also developing specialized care for dying people in hospices in Europe, Asia, Africa and in the Americas. Although the care provided were limited compared to the standard today, those early principles became the foundation for modern palliative care. A holistic approach to pain management involving physical, psychological, social,

and spiritual care was introduced by Cecily Saunders who created an advocacy for dying patients in the 1960s (Saunders C., 1964) This approach was welcomed by many hospitals, including St Christopher's Hospice founded in 1967, which incorporated research and training. Her influence gained global recognition gradually, and through activism, it became an established practice. Although at the initial stages, palliative care was restricted to management of cancer patients primarily as new competency surfaced in the use of opioids. The term 'palliative care' came into use in the 1970s and the coining was credited to Balfour Mount, (Mount B., 1997) signalling the incorporation of the principles and practice of palliative care beyond Hospice, into broader hospital settings from specialist center to primary care, and even to the homes of patients. As this new field of research and knowledge emerged journals were created to disseminate findings and international and national societies were formed.

The World Health Organization have played a central role in the development of palliative care. In 1986, undertreatment of cancer was acknowledged as a major public health challenge thus the WHO published the famous pain relief ladder with recommendations on analgesic usage in mild to severe pains (WHO, 1986). In just a year after that, the UK formally recognized palliative care as a specialty in medicine. To clarify the comprehensive nature of palliative care, in 1990 the definition palliative care that emphasized pain and symptomatic relief was given by World Health Organization (WHO | Cancer Pain Relief and Palliative Care. Geneva, 1990), followed by a 2002 revision that broadened palliative care services beyond cancer treatment (Sepulveda C et al., 2002), since then palliative care started developing gradually on a global scale. 2014 witnessed a landmark resolution involving palliative care at the first ever World Health Assembly on palliative care (World Health Organization, 2014). Its resolution called on members and Governments to incorporate palliative care into the health system to be delivered at all levels (Knaul et al., 2018).

Palliative care is defined by the World Health Organization (WHO) as "an approach that improves the quality of life of patients and their families facing the problem associated with life-limiting or threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." Palliative care does not hasten or postpone death, rather it provides relief from pain and other distressing symptoms focusing not only on physical symptoms but also on

emotional care through psychosocial and spiritual support. It affirms life and offers a support system through team approach to assist patients live as best as they possibly can. The support it offers is also extended to family members and guardians to help them cope during the patients' illness and in their own bereavement. Palliative care is usually commenced as early as the diagnosis is made, while patient is receiving curative treatment in conjunction with other therapies, such as chemotherapy or radiation therapy. When care is given early in the diseases, it may result in positive influence in the course of illness (*WHO Definition of Palliative Care*, 2011).

To clarify how comprehensive of palliative care is, the WPCA policy statement on defining palliative care further emphasizes that palliative care is needed in chronic as well as life-threatening and limiting-conditions, without time or prognostic limit on the delivery of palliative care and that palliative care should be provided at all levels of care and in any setting, which may include "patient's own home, a care facility, hospice inpatient unit, hospital, or outpatient or day care service" (Connor et al., 2014). Furthermore, the need for palliative care does not overshadow the importance of preventive health services and curative treatment. A similar but quite different concept is Hospice care also known as end-of-life care, which is the end of life care by health professionals and volunteers involving medical, psychosocial, and spiritual support to help patients who are dying to have peace, comfort and dignity (*Definition of Hospice. MedlinePlus*, n.d.). The main focus in hospice is controlling pain and other distressing symptoms arising in patients while also supporting families. While there are several overlap between palliative care and hospice care in caring for patients with chronic, life-limiting or life-threatening illnesses, a major difference is the time frame in which the care is provided. Palliative care tends to be provided early in the course of the diseases, often commenced after the diagnosis is made, in conjunction with curative treatments and intervention such as chemotherapy and radiotherapy. Hospice care on the other hand encompasses care provided when the disease is no longer responsive to curative treatments, it focuses on controlling symptoms with comfort and dignity, and peaceful death in the patients last days.

Relationship between palliative care and curative treatment

The Worldwide Palliative Care Alliance recommends integration of palliative care alongside curative care into the healthcare system by Governments. At a very least, palliative care should be provided even when curative care is unavailable. (*WPCA Policy Statement on Defining Palliative Care.*, 2013) There are several factors that may affect this relationship depending on countries and societies. At any rate, palliative care bodies emphasize that in no way should palliative care substitute appropriate curative treatment. Although modern medicine places higher emphasis on therapeutic measures, it is important not to neglect palliative measures. In some high income countries curative treatments may be giving greater priority, leading to delayed commencement of palliative care which could be provided alongside. On the other hand in some low and middle income countries, curative treatments may be limited or even unavailable, in this setting palliative care is very essential. Still, it should not be considered as an excuse for not developing the health system to ensure curative treatments are available to patients suffering. Provision of such care may involve efforts to challenge cultural misconceptions and stigmatization of death. (Connor et al., 2014)

Holistic approach to palliative care is a comprehensive care given to patients as embedded in the WHO definition. It should address patients and their families or care givers physical, emotional, and spiritual issues, in addition to other logistical issues. Physical symptoms often involve pain management, and other symptoms like difficulty in breathing, nausea and vomiting, diarrhoea and constipation. The diagnosis of chronic or life-limiting illnesses is usually accompanied by different emotions such as fear and anxiety, depression and thus the need for psychotherapy to manage stresses and emotions emerges. A palliative care team often include the services of chaplain, responsible for spiritual care of patients and their families, providing comfort and spiritual guidance. The anxiety and stress that comes along with the illness may crowd patients judgement and their families such that caring for relatively minor logistical issues becomes a challenge, thus the palliative care team typically provides the necessary support when it comes to financial, legal, and employment concerns. Some of the study from Africa indicates that the greatest needs facing majority of patient with serious chronic, life-limiting illnesses and their

caregivers may be psychosocial with basic socioeconomic deficiency which include food shortages, adequate shelter, and patients inability to the school fees of their wards (Herce et al., 2014).

Diseases requiring palliative care

Typically, palliative care focuses on non-communicable diseases in addition to other chronic diseases such as Tuberculosis and HIV/AIDS. However, the burden of disease varies depending on country or region. Based on data from WHO (WHO | Global Health Estimates, 2013) the diseases of adults requiring palliative care include cardiovascular diseases (38.5%), cancer (34%), chronic respiratory disorders (10.3%), HIV/AIDS (5.7%), Liver cirrhosis and diabetes(4.5%), other illnesses include Alzheimer's disease and other dementia, Parkinson's disease, and chronic kidney disease. The prevalence of HIV of among the reproductive age group (15-59years) has been associated with rise in tuberculosis. Consequently, the high proportion of those in need of palliative are young population being managed for HIV/AIDS, whereas older age group predominantly have Alzheimer, chronic respiratory disease, rheumatoid arthritis, and cancer. On the other hand, diseases of children (<15 years) needing palliative care generally differ from those of adults. Cancer, cardiovascular diseases and congenital heart diseases and other congenital anomalies, liver cirrhosis, haematological disorder such as sickle cell disease and immunological disorders, HIV&AIDS, meningitis, renal diseases, neurological disorders, and other neonatal conditions.

Models of palliative care services

Hospital based palliative care services are provided within the hospital either in the context of stand-alone outpatient clinic, this is regarded as a low-cost model, and can be the best model when combined with inpatient consultations and in combination with a palliative care consultation service for inpatients within the hospital. Ideally, the team includes a doctor, a

nurse as well as a social worker, often included is a spiritual care provider – a chaplain. Not so much effort is required to include hospital inpatients consultations to an already established outpatient clinic, this can potentially help in capacity building in palliative care and pain relief with other staff in the wards. Other options for hospital-based services include palliative day care service, in patient palliative care unit and outreach programs. A day care facility may improve services and the day care might be used as a procedural room for care such as physiotherapist, ascitic fluid drainage and for training purposes. It can also be used as a social gathering venue for patients. On the other hand, an in-patient palliative care service unit has beds specifically for palliative care with trained workers available to render services throughout the day. An advantage of this system is the consistency and continuum of care provision for patients and their families or guardian. In addition, symptoms control is easier due to availability of diagnostic and therapeutic options. A palliative care outreach is one that reaches out to patients, especially those with difficulty reaching the facility and taking the mobile service close to them or at the homes of patients, this way it is able to motivate caregivers not to give up in helping patients. “A hospital-based service generally reduces a patient’s length of stay in hospital and enables a smooth transition to care in the community” (World Health Organization, 2016).

When palliative care services are provided at community health centers with the participation of community volunteers this is termed as community based palliative care. It is quite different from hospital based palliative care services that relies primarily on the services of doctors, nurses, perhaps social worker, and a chaplain in some cases, within the hospital setting. Within the community health centers there are medical staff as well as technicians and assistants who are trained in safe handling of opioid medication and palliative care services, which they do in partnership with available human resources, these support the community health workers or volunteers who visit patients at home in the community irrespective of their financial endowment.

In home based palliative care model, a multidisciplinary team, often including the clinical staff and non-clinical staff visit patients in their homes, to provide physical, psychosocial and spiritual care to patients and their families. This may be an add-on service for hospital-based care or community-based care. A study demonstrated that for optimum home-based palliative care, a

good collaboration and dialogue must exist between the providers and patient and their family (Danielsen et al., 2018). Literatures have identified a number of advantages to the home-based palliative care model in different situations, among which are cost effectiveness, ease of access, easy integration of family members and confidentiality (Gomes et al., 2013), (Brumley et al., 2007)

The latest evolving model of outpatient palliative care clinic is the Ambulatory Palliative Care Clinics. (D.E. Meier & L. Beresford, 2008). More focus has been placed on inpatient palliative care services in the past decades, however, the ambulatory palliative care services is rapidly growing and it presents a number of advantages (D.E. Meier, et al., 2010). Typically, it works also with interdisciplinary team of physicians, nurses, psychologists, social workers, chaplains and other relevant team members, who focus on improving the well-being of patients and their families suffering from chronic or life limiting illness

A Study conducted in Neno district of rural Malawi showed patients preferences. Most patients preferred home based care (46%), followed by community-based services at a nearby health center (30%), and hospital-based care (24%); with only 1 of the 50 answer favoring concept of hospice. On the other hand, caregivers too had different preferences for venue of service provision with 46% opting equally for home-based care and community-based care, and 36% referencing hospital-based care. Most reported wanting the support of a village health worker, and other forms of community support through volunteers (Herce et al., 2014).

Justification

The research gaps

Up till now, research on palliative care in Malawi has primarily focused on prevalence (R. Harding & Higginson, 2005), unmet needs (Downing et al., 2010) , and on access to medication (Tapsfield & Jane Bates, 2011). One quantitative study has done family assessment of treatment at the end of life of war victims (Casarett et al., 2008) and another qualitative study has identified fear among health care providers and care recipients related to prescription and use of morphine as a major barrier to adequate treatment (Bates et al., 2008). However, there is a dearth of knowledge about the provision of palliative care on primary care level as experienced by adult patients suffering from life threatening and terminal illness. This project addresses this gap through a qualitative investigation of palliative care practices extending from hospital to home, and explore the experiences of the palliative care team members on one hand, and on the other hand, the patients and their guardians enrolled in the palliative care program in the hospital, and/or at home of those living in Nkhoma hospital catchment area Malawi. With limited knowledge on how the project is perceived and experienced, there is a need for a broad explorative study to document both strengths and weaknesses in its implementation. These qualitative findings may form the basis for further studies. This is also the first research at master's level carried out in the department since the commencement of the program.

This research discusses policy, training, access barriers and socioeconomic challenges that remain for palliative care to attain full integration even in the rural communities . Although there have been several efforts to describe palliative care coverage in Africa (Lynch et al., 2013) as a whole, few have focused on Malawi. (Herce et al., 2014) (Tapsfield & Jane Bates, 2011) (Bates et al., 2008). No recent studies have been published that explored experiences of palliative care providers and care recipients since the recent capacity building in palliative care began about 5years ago at Nkhoma Hospital.

Aims and Objectives

The main aim of the research is to investigate the strengths and limitations associated with provision of palliative care as experienced by healthcare personnel and patients in the palliative care programme at Nkhoma Hospital, Malawi.

Specific Aims

- Describe the provision of palliative care and the role of the palliative care team
- Identify challenges associated with the availability and use of morphine within the hospital catchment area
- Explore health worker's perceptions and experiences in providing palliative care to patients and support to their relatives
- Explore experiences of patients and/or their relatives in pain control and management of other physical symptoms and psycho-social and spiritual support

Overall, it is hoped that the study contributes to the improvement of palliative care in the low resource setting of rural Malawi, by strengthening the evidence base needed development of Nkhoma palliative care program.

Methodology

Study Design

A qualitative study design has been chosen as it allows for the in-depth exploration of the perceptions, experiences, and practices of both the providers and care receivers in the field of palliative care in the selected region. Qualitative methods are used when answers are needed to question about experience, meaning and perspectives, unlike in quantitative methods where the problem is unambiguous, and variables can be linked to form hypotheses before data collection and as such involves measurements and counting. However, in a quote often attributed to Albert Einstein, it is said that ‘not everything that can be counted counts and not everything that counts can be counted.’ This was in fact the theme of an article in the *British Journal of Pain* that encouraged further exploration of qualitative research especially for studies on understanding of pain, and to spark interest in the methods (Toye, 2015).

Through qualitative approach primarily, a situation analysis was conducted using techniques similar to the rapid evaluation methodology (REM) which was designed by the World Health Organization (WHO) for collection of data through field-based interviews along with observations. Findings and recommendation based on this methodology has been used in scientific publications, including those about palliative care services in sub-Sahara Africa to guide quality improvement efforts by planners and decision-makers, and provide a basis through which operational problems can be identified for managerial action to be taken (Anker et al., 1993).

Study Setting

A visitor will readily notice that Malawi is a densely populated country while travelling from the Kamuzu international airport to Nkhoma hospital in a journey that would last over 90 minutes. Along the way, one cannot help but admire the beautiful landscaped with towering mountains and the mesmerizing sunset. Within Nkhoma region is the Nkhoma mountain, which is one of

the several natural beauties within the area. Interestingly, this landmark is used in the logo of Nkhoma hospital with the motto: “serving with love and care”. The view of the immediate environment of the Nkhoma hospital appears greener from the Nkhoma mountain, owing to the tall and huge trees surrounding the region.

Figure 2: Map of Malawi, with dropped pin at Nkhoma, located within Lilongwe district. Adapted from CDC (CDC, n.d.).



This study was conducted in Nkhoma Mission Hospital (NMH) and communities in Nkhoma catchment area of rural Malawi. NMH is located about 60 km east of the capital Lilongwe, where the Kamuzu Central Hospital is located. The catchment area is the surrounding rural community, serving a population of more than 75000, most of them living in 260 small villages up to 40 km from the hospital, some patients even come from Mozambique. The catchment area has 10-12 Healthcare centres located in the largest villages. NMH was established in 1915 and is now a 220-bed facility. It has about 17,000 inpatient visits and 46,000 outpatient visits per year, it also conducts mobile clinics throughout the catchment area. The study site included homes of

patients living far away from the hospital, that were visited during the home-based care within the catchment area. Some of these patients live in isolated huts scattered all over the territory in mountainous regions difficult to approach.

This secondary level hospital attracts nursing and medical interns, as well as resident physicians and specialists from different institutions in Malawi and abroad, such as from the Netherlands, Germany, Sweden and United States, making it a multinational community, with interchange of knowledge, experiences and expertise.

Study participants

The study population is comprised of the team of palliative care providers, and care recipients. Within the team are clinical officers, nurses, medical assistant, pharmacy technician, agricultural extension worker serving also as the nutritionist, chaplain and community health volunteers. The other category is the care recipients and their guardian, that included selected patients enrolled in the palliative care project at Nkhoma Hospital and their relatives or guardian. Twenty (20) participants were interviewed, and although data saturation was reached earlier than expected, the interview continued until 10 participants in the first category of healthcare providers and 10 in the second category the patients and their guardian were included. In addition, I observed palliative care services provided to upward of thirty (30) patients. This number is big enough to obtain a broad perspective, and few enough to allow in depth exploration of their conditions. The number of study participants were decided based on data saturation and availability and willingness of patients and their families to participate in the study.

Recruitment of participants

The first 2 weeks at the department involved getting to know the hospital and the various departments, meeting members of the palliative care team as well as studying the files of the patients, which provided insight into the common diseases being cared for in the department and the line of management, especially for the physical component. Recruitment of members of

the palliative care team was done thereafter, while patients/relatives recruitment spanned over a longer period to ensure a purposeful selection of participants among those presenting to the hospital.

Care providers

Most of the participants purposively selected for the semi-structured in-depth interviews were asked in person, others were electronically informed and a date for the interview was proposed subject to participants convenience. Following a positive confirmation, the time and venue were then scheduled. A purposive 'sampling' or selection method is beneficial for obtaining perspectives of the various cadres of the healthcare providers in the team.

Care recipients

Patient's records were used to identify potential candidates for the interview. This was done to include cancer patients, patients with HIV/AIDS and other chronic/life-limiting diseases such as Liver cirrhosis, male and female genders, old and young (children were excluded on ethical grounds) and patients living near and those living far from the hospital. Some of the interviews also included patients' relatives (guardian). Having different perspectives from those with various background as experiences increases the likelihood of shedding light on the subject (Graneheim & Lundman, 2004)

Inclusion and Exclusion criteria

Included in the interviews were adult patients enrolled in the palliative care, able to provide informed consent, and relevant information in terms of disease progression, pain and other symptoms. Excluded from the study were children below 18 years, as well as those unable to provide informed consent and patients who are too sick to participate. Representatives from all the cadres of health workers in the team participated in the interview, as well as from the chaplaincy and community volunteers.

The table below shows the distribution of the participants in the interview.

Distribution and characteristics of participants in the in-depth interview			
Palliative care providers (n=10)		Care recipient's diagnosis (n=10) *	
1	Nurse (coordinator)	1	Cancer of bladder /cervical cancer
2	Clinical officer	2	HIV and Liver cirrhosis
3	Nurse 2	3	HIV, TB, and Liver cirrhosis
4	Chaplain	4	Cancer of the cervix
5	Nurse 3	5	Cancer of the cervix
6	Agric extension worker (nutritionist)	6	Kaposi Sarcoma/HIV/TB/ Cervical cancer
7	Pharmacy technician	7	Kaposi sarcoma/HIV
8	Medical Assistant	8	Cancer of the cervix
9	Community health volunteer 1	9	Sickle cell disease
10	Community health volunteer 2	10	Stomach cancer/recurrent hypoglycaemia/ Asthma and Hypertension

**this does not include the guardians who were present or who took part during the discussion*

Methods of data collection

The fieldwork took place between 15th of July and 30th of September 2019 and it included both hospital-based and home-based care components. Several methods of data collection were used to ensure accuracy, trustworthiness, and reliability of data to strengthen its applicability in improving palliative care services at Nkhoma, Malawi. Data were gathered from the clinic documentations, health staff interviews, observation of task performance and observation of facilities and supplies, group discussions, patients (clinic-exit) interviews, as well as household

interviews. The use of two or more sources of data may strengthen the comprehensiveness of findings is referred to as triangulation (Mays & Pope, 2000).

The clinic documentations were among the first data to be reviewed during the first few weeks of arrival at the unit. These documents provided a broad understanding and overview of the activities of the team as well as common cases requiring palliative care in the region. They also supplied data on the number of cases registered, diagnosis, treatment modalities and the frequency of clinic appointments and attendants.

Health staff interviews were done to gather information from palliative care providers through face to face in-depth interviews with the participants in English Language. The use of in-depth interviews allows the researcher to have first-hand information on the participants' perceptions, experiences, attitudes, wishes and aspirations towards palliative and end of life care. Data from the interviews were captured electronically using a passworded mobile phone after obtaining an informed consent (see Appendix 2) from the participants. This was done to retain accuracy, reproducibility, and credibility of the collected data. Semi-structured adjustable open-ended interview guide (see Appendix3) was designed for the palliative care providers and for the patients to help guide the interviews. Averagely, the interviews lasted about an hour, although no fixed time duration was allotted it, as circumstances of participants vary.

The focus of the interview with the health personnel was to collect information on structure and organisation of the team, how the work is organised as well as how members collaborate as a team, how they include patients and do follow ups. Information was also gathered on their training and experiences, community integration, perception of the care given to patients, challenges and recommendations. On the other hand, the interview with patients and guardian focused on their experiences, needs, care and respect, discrimination and how informed they are about their disease and its prognosis, follow up plans, and their perception of the care received from the palliative care project. They were also encouraged to voice the challenges they face with regards to symptom control, economy and other anxieties and uncertainties.

Patients clinic-exit interviews were conducted with the help of a research assistant in the local language of the participants - Chichewa, since almost all the patients prefer the local language.

During the in-depts interviews that lasted about an hour, patients shared their experiences, disease progression concerns and challenges. In addition, household interviews during the few home visits afforded the researcher an opportunity to involve family members, and guardian. It is also easy to understand the social-economic challenges of patients, which is very important in palliative medicine.

Another source of data was active participatory observation. In the capacity of being a medical doctor, I was able to assist with some consultations with patients, within the scope of my active participatory observation which also involved the researcher's observation of team members as they performed their routine duties. It also created a more relaxed atmosphere for the care recipients to express themselves freely since the researcher was perceived, not just as a stranger, but as a member of the team working in their best interest. Since the participant observation lasted all through the 3months, I had a chance to observe the social and professional interactions between the members, and care provider-care recipient over time. Observations and experiences gathered through the participant observation were documented in the field notes / observational diary as soon as possible to ensure accuracy and eliminate recall bias. The aim of the observation was to gain insight into the day to day palliative care work at the department, to map infrastructural challenges and daily routines and the interaction between the care providers and the care recipients in these encounters. Observation also took place during home visits, with the aim of getting to know the context of the home-based care, the resources available, the living conditions and daily care provision at home and the interaction between the home-based care team and the patients and their care givers.

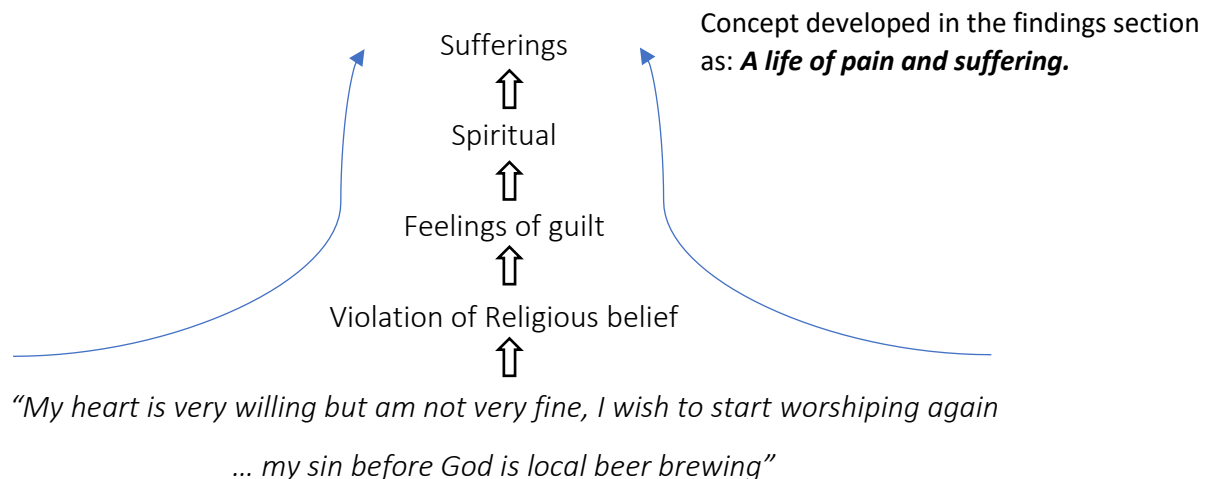
Group discussions through meetings served an important role in data collection in this study, because individual group members expressed varied opinions. During the weekly meetings, team members discussed the challenges facing the unit, with the aim of improving services provided. I was able to ask questions during or after these discussions, and this provided insight into the challenges faced by the team.

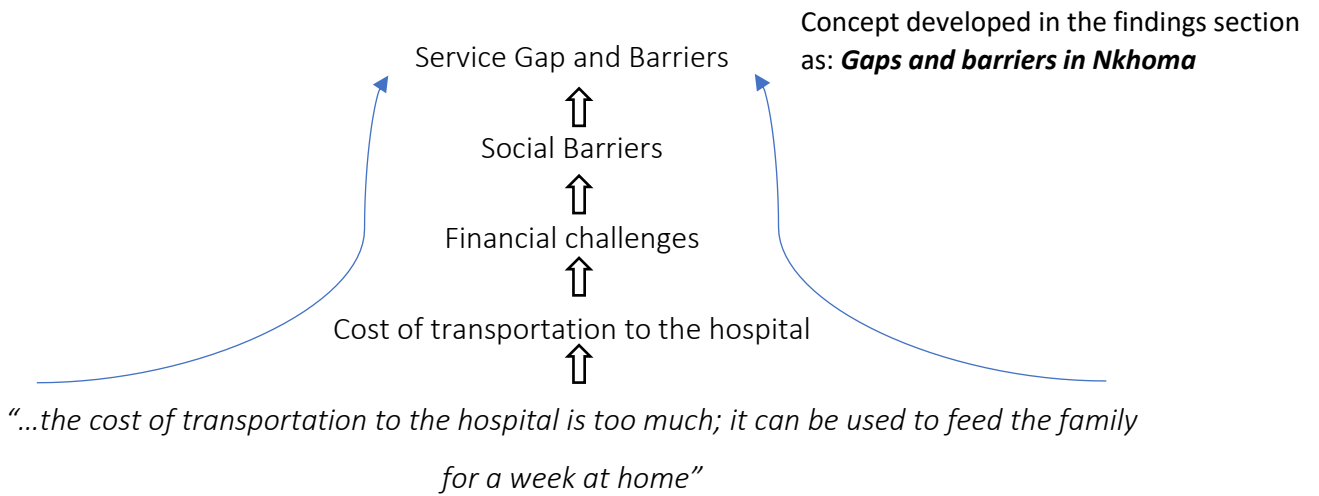
Qualitative data analysis

The interviews were recorded using a passworded mobile phone. Recorded interviews were thereafter transcribed verbatim. Since interview with most of the patients were done in Chichewa, a research assistant was used to transcribe and translate the text into English. Some of the English transcripts were crosschecked with the audio recordings to ensure no error in data entry. The analysis of the interviews and observations followed Malterud's analysis framework, which is a modified version of Giorgi's phenomenological analysis (Malterud, 2012).

Malterud's systematic text condensation has been described as a "descriptive and explorative method for thematic cross-case analysis of different types of qualitative data." It can be used for in-depth interviews, observational studies, and in the analysis of writings while giving enough latitude to diverse theoretical frameworks. There are four steps involved, the first step is getting a total impression, thus moving from the initial chaotic data to themes followed by identification and sorting out of meaningful units, thus from themes to codes. The third step is condensation of the data from code to meaning and finally ending up with the fourth step of synthesis, from condensation to descriptions and concepts. There are a number of similarities and some differences when compared to other systematic text condensation often used in qualitative research (Malterud, 2012). In addition to this inductive analysis, I used my research questions deductively to define themes related to the palliative care organisation at Nkhoma.

Two examples of text analysis are shown below:





		DATA ANALYSIS				
			No motorable roads			
		Transport fare	Transportation cost			
		Cost of surgery	Escort	Traditional healers		
		Cost of other drugs	Exhaustion	Religious healers		
		MONEY	DISTANCE	CONFLICTING IDEAS		
		BARRIERS			BARRIERS	
			SUFFERINGS	CARE RECIEPIENTS	CARE PROVIDERS	
			FACILITATORS			FACILITATORS
		SYMPTOMPS	COST	CARE & RESPECT		
		pain	free drugs	Improvements		
		bleeding	free consultaion	feel respected		
Pain Bleeding Diarrhea Constipation Pruritus/itch Difficulty breathing Guilt Neglect Social Isolation Family break-ups Financial suffering Lack of housing Malnutrition Discrimination	PHYSICAL PSYCHOSOCIAL					Financial Training Scanty evidence-base Personnel Policy Infrastructure Follow up Sustainability Drug availability NGOs support Drug availability Research Training center Personnel training Screening programs

Based on the analysis the following major themes and concepts were developed: A life of pain and suffering, Palliative care at Nkhoma, Organization of Nkhoma Palliative care services and Gaps and barriers of Nkhoma palliative care program.

Ethical considerations

The importance of an ethical research cannot be overemphasized in a scientific study. The proposal went through and received approval from the Norwegian Ethics Committee (REK-West) and the responsible ethical board in Malawi - National Health Sciences Research Committee (NHSRC). To comply with ethical considerations in conducting research, potential participants were provided with information sheet that explained the purpose of the study and they were informed that their participation in the study is voluntary, and that they have the right to withdraw at any time before or during the study/interview without any consequences.. Thereafter, willing participants provided verbal and/or written consent, using the consent form. Permission to record the interviews was obtained from each participant while their identities were kept anonymous. Oral consent was obtained from study participants during observational part of the study. The information is kept safe and is being used solely in line with the purpose of this study.

Each participant was given a unique identifier, and this number was used when storing forms. The project collected sensitive medical data on patients' diagnosis, treatment, history of illness and experiences with disease as well as satisfaction with the palliative care services, provided through the hospital and through the home-based care team as experienced by both the patients and relatives. Patients access to and use of morphine were also noted. The sensitivity of these data made it particularly important to protect the data from accidental loss or unauthorized access.

Harm or Benefit

The research does not involve any intervention or experiment and does not carry an increased risk to the participants. There is no individual harm or direct instant benefit that comes from participating in this study. However, a previously undisclosed modest provisions were made available to compensate for the time of the participants and/or efforts in participating in the interview. According to Lee and Kristjanson, wrote about challenges associated with palliative care research, still they noted that without research taking place, there is a risk that nothing new

is attempted and that there could be a failure to scrutinize how the profession cares for dying people. Also, palliative care researches help to demonstrate and justify the value of palliative care services, which in turn can attract the attention of global health actors (Lee & Kristjanson, 2003). Describing palliative care research, Seymour and Skilbeck noted that it requires striking a fine balance between the ethical duties of providing caring support, nurturing independence and autonomy, and achieving research outcomes (Seymour et al., 2016). Besides these, other outcome of this study is that it shows policies, trainings and guidelines that have worked so far and highlight what should be done to improve service provision. This study may also form the basis for further quantitative studies.

Findings

In this findings section, the first section which is called 'A life of pain and suffering' is a description of the patients enrolled in the palliative care program at Nkhoma, and how they struggle to cope with pain and survival. Thereafter, I moved on to describe the palliative care team and the common cases they attend to. The third section entitled 'Organization at Nkhoma palliative care services' provides a thick description of the various facets of care provided as well as the palliative care models used to meet the patients' needs in the hospital and at their homes in the community. This chapter concludes by focusing on the challenges, that is, the gaps and barriers that potentially limits the services and care provided to patients and their relatives.

To begin with, the hospital is considered by participants as a secondary level hospital, that is, a district hospital. The staff is comprised of locals and foreign workforce with nursing and medical interns, as well as resident physicians and specialists from different countries such as the Netherlands, Germany, Sweden and the United States, resulting in interchange of knowledge, experiences and expertise.

A life of pain and suffering

Although Malawi is generally considered a densely populated country, most people are dispersed in rural areas in the villages. Thus, making accessibility to healthcare one of the major challenges, particularly for those living in the rural areas. As pointed out by participants, many are already plagued by food scarcity and malnutrition in addition to poor housing and living conditions resulting from poverty. As such, being diagnosed of a life-limiting disease, in addition to these other challenges, in the absence of a social security system, was a nightmare to all the participant. For example, a young 35-year-old male participant on chemotherapy, paused, looked back at his life and said with tears: *'I feel sorry and pity for myself, my life is not good, I feel that any time I can die. That's why I was feeling something not good.'* He lamented that his family depended on him and that he got the diagnosis while still *"searching for better life, because my parents' families are very poor."* Participant 17

When patients are diagnosed of life-limiting or life-threatening diseases, not only does it add the burden of physical symptoms like pain, it also comes with a whirlwind of negative emotions and in some patients – dependency and isolation results. At Nkhoma, the psychological and social needs of patients tend to predominate. That is why I would be describing these components first, using real-life examples of patients that took part in the interview.

"I am more like a small child now"

A person whose health has limited his or her ability to produce maize is invariably being sentenced to hunger in the absence of assistance from others. This leaves the sick and weak very helpless and vulnerable. Several participants explained that due to their illness they are no longer actively engaged in the cultivating activities which makes them dependent. On informant explained below that due to her illness she has been unable to produce maize, leaving her feeling helpless and dependent on others:

“... it’s two years now without producing maize (farming) because of my sickness, I depend on my parents for everything, for instance to purchase soap and salt; I am more like a small child now” Participant 16 a middle aged woman diagnosed with Kaposi Sarcoma and HIV/AIDS as well as Tuberculosis and Cervical cancer.

She said her children are still young, and she is separated from her husband. The patient believes it is her responsibility as an adult to provide not only for her young children materially but also for her ageing parents. Inability to meet up with these expectations have triggered feelings of worthless and helplessness, especially as she still had to depend on the parents. She had since relocated to her parents' place together with her kids, fully dependent. These feelings go along with hopelessness as a result of her multiple diagnosis of Tuberculosis, Cancer of cervix, HIV and Kaposi sarcoma. But she claimed to have been receiving some emotional support from her church. She tries to shield her children from the emotional trauma, but notices the impact it is having particularly on her eight-year old child of whom she said: *“... my younger child is very dull these days due to my sickness, especially when I fall very sick and lay down.*

The issue of lack of food security, and potentially the lack of ability care for one’s children and parents due to the chronic illness were recurring concerns for a number of the patients followed up by the palliative care team. Describing this situation, a team member said

“...when we visit our patients, you find out that maybe that patient is lacking food...and when we come back here, we find out that we have no food to help the patient...”

In addition to poor nutrition, shelter or housing is another basic amenity many patients lack, some homeless, others live in dilapidated structures, sleeping on the mud floor because of lack of bed and beddings. The sufferings associated with poverty is hard to describe, most of the patients live far below standard living conditions. One informant, a middle-aged woman, diagnosed with cancer of the cervix said:

“I sleep on a tent (sack), I had a mat but my son who has a psychotic condition took it away, he also took my pots and plates to sell, I begged for two pots at the market, if I have food, I cook using those pots... I have a grass thatched house with two rooms, I eat

the food supplement I receive here, I eat Nsima with either okra or cabbage. I can afford meat once in a month, I usually afford buying fish after sells, mostly I bought maize from the sales.” (participant 15)

Living in a grass thatched house (see image 2) that is not well maintained due to lack of energy for some of the informants implied getting soaked inside the house when it rained and this became worse in the rainy season. During the dry season, the grass dried off which would require replacement. When the patient was asked about her diet, she explained that she does not eat fruits. She primarily eats maize, and her diet hence has little or no variation due to the costs of other foods. The conversation below is an excerpt from the interview transcript with participant 15, diagnosed of cancer of the cervix, that describes her nutritional state and most of the patients:

R: How often to do eat fruits?

Pt: I can't afford fruits; I'll rather prioritize maize, because these days I can't produce maize.

R: so, besides maize do you eat other foods?

Pt: mostly I eat maize, in porridge - 'Nsima'

R: when last did you eat any other food, other than maize products. For instance, rice?

Pt: hmmm, when I have money, I can just afford a cup of tea.

Social suffering experienced by the patients are derived from several sources, these include extreme poverty, inadequate food and nutrition, lack of housing and clothing. Many families struggle with financial set back due to serious illness of a family member, or death. Many patients are unable to support themselves and their families, so the palliative care workers are having a hard time funding these needs, because according to them, there is no dedicated funds solely to take care of patients' social needs. Even though they try to address the social suffering at times. I have observed medications being served to patients on admission without food, even injections given on an empty stomach, it is for this reason a patient said: *"I experience dizziness soon after taking the medication."* Another team member, participant 1 explained:

“...We find patients homeless, others without beddings, others without food yet they are taking medication. They really struggle. They are in pain. They have stopped doing their businesses and working as before (because of illness). They have been sick for several years and the only hope for them is the hospital. So, we really feel sorry for them and we are praying that we can have help from other bodies, it will do us good, sure.”

Some were not as helpless initially but when circumstances changed, things became worse. This was the case with an elderly woman probably in her late 50's whose circumstance changed from 2001 onwards and then became worse after being diagnose with an advanced cervical cancer, she explained:

“...I am homeless, my husband died of hunger, during the drought, he died of hunger. We had drought for the whole period, so, he died as a result of that drought because there was no food. Many men died in 2001-2002 because they were the ones who used to search for food, the little he was able to get during the period was what myself and the children managed, so my husband died trying to fend for the family he had nothing to eat during the period, afterwards with the children we were working on other people's farms to survive.”

Up till the moment, she struggled with both psychosocial pain and physical pain. Her story continues in the next chapter, with the description of her physical and spiritual pain

“I feel a lot of pain and...I don't find peace at all”

– the story of participant 18

This patient receiving palliative care on account of cancer of the cervix described more about the onset and the effect of her physical symptoms is having on her. She said

“It starts with three days of no toilet visiting, it follows that all day heavy and continuous bleeding with burning pain in my vagina and anal area, ...this is what has been my life

these days ... I am even failing to sleep these days. I visits the toilet feeling that its nature calling then the bleeding starts again, the bleeding takes the whole day through the night before it stops...Then I just suffer the vagina pains, I don't find peace at all. I have been like this since I got joined palliative care, I can't go out to chat with friends, I have been in bed since then."

Physical pain can come in various dimensions, besides the pains and bleeding the patient presents with, a team member said others may present differently *"Patient comes crying with severe pain. others come with fungating cancer that is smelling. Sometimes people are vomiting, people have got abdominal distension and it is causing discomfort, anaemia, shortness of breath., inability to swallow..."*

Thinking about the future of her children has been a cause of unceasing concern and pain for her participant 18. Speaking about her children the participant continued

"...they never attended secondary school level because of the fees. The one who attended highest level was standard 8; (last level in primary school). I cannot manage paying the fees for my children...I am sick, and my thought are stered,"

This has made her feel like a failed mother she said *"I am sick, and my thought are stered, I have not any plan for my children since I am sick. I borrow from the village savings loan groups hoping that when I will get better."* This patient managed to get enrolled in the palliative care program but still have to travel from the village to Nkhoma hospital, this is a significant challenge and barrier for her, she explained the financial implications of journey saying:

"...The cost of transports is 4000 kwacha per head to and back. 8000 kwacha if two people, no discount, I always come escorted because of the pain, when my condition is really worse two people bring me, when it's a bit better like today it's one person... sometimes it goes like that, I have to pay up to 16,000 kwachas (NOK 225)for us" (1NOK is about 71MWK)

I asked her about the implication of that spending on her household and she made clear that the amount spent on transportation to the hospital was enough for the whole family *"for a week."*

She has received some gifts from the palliative project in the form of clothing, soap and the likes. However, it appears that she would prefer food stuff such as maize flour. She said *“you give me clothing, soap and the like, I do appreciate that. But if you may be giving us food for instance ‘Nsima’ (a staple food in Malawi, made from maize and hot water) I can’t produce that due to the sickness, they advise me to eat but I don’t have enough food to eat.”*

The story of participant 18 is just one among the other participant and patients who in addition to the burden of the illness physically, had serious concerns due to food shortages and lack of funds for basic necessities such as travel to the hospital and school fees.

“I don’t play... because I feel too weak”

Sickle cell disease is the commonest disease in children requiring palliative care at Nkhoma. A 19-year-old boy, who is currently out of school because of his illness commented on his experience along with his dad in the narrative below

“I was in standard 6, not going to school again due to the sickness, it started when I was young... I was feeling paralyzed in both the hands and feet, starting with the big finger in my hands. That is the origin of the sickness till today. It took two months before they took me to the hospital, I then fell sick, my whole body including the feet was swelling.”

The father, who also joined the interview added:

“my son was born in 2001, he started with swelling of one leg and the hand of opposite side at two weeks old, this was interchanging like that. We went to (X) health centre, it did not work, we took him to (Y) health center, it still did not work. We then came to Nkhoma where they admitted him. He had ‘tumours’ on the leg and hand of opposite side where they operated him. The wound took a week then it started healing. he reached 5 years in a stable condition, but he was experiencing fever too frequently. He developed anaemia at age 5, He received blood thrice from age 5 through 6th year. It has been the case from then. I have donated blood for 5 times to him. He has received blood for 11 times from 2001 to 2017. And I have donated blood to him for 5 times.”

The father who appeared bitter over the son's condition was questioned about his feelings. In response, he explained that the family has been divided (apparently, he dismissed his wife) and that he is blaming the wife because *"this kind of disease run in their family line."* He apparently had a justification for his claim, saying:

"...my sister in-law has similar problems, her 8- year old child has same problem, it seems this problem is inherited from their parents, that child experience similar problems as my son."

"Nobody in my family had this disease" he added. At that, I had to go a little off track to educate him that it takes two to tango. In the case of sickle cell disease, it requires equal contribution from each parent. As expected, it came across as a surprise to him. This underscores the importance of educating patients and their family about the diagnosis, perhaps if he had known this, the wife would have been spared on much heartbreak and the family could have been saved of the psychosocial suffering.

The translator explained that typically in Malawi before marriage, *"we just do HIV test, we don't undergo further tests."* This explains why most children registered in palliative care are suffering from the life of intense pain that result from have the life-limiting sickle cell disease. The boy continued to describe what happens when he is in crisis, even when he is not in crisis, he is unable to socialize with his colleagues. He said:

"...I experience severe headache and I develop a hump on my stomach which pains much ... Many times, I stay idle, I don't play, not because I don't want to, but because I feel too weak if even if I play a little."

Thereafter, I asked him about his experience so far with palliative care at Nkhoma hospital and how he is feeling at the moment, in response he said:

"they give me a warm welcome but sometimes it takes long before I receive medication, I may wait on the queue for an hour ... I feel better, the pain has reduced but I still have burning sensations in my heart and fatigue when I am taking a walk. Sometimes I experience vigorous heart beats."

The father of five is uneducated and poor. Now that he has been referred to Kamuzu central hospital, his hope is ignited, believing his son will receive a permanent cure there, perhaps in the form of a wonder drug. Unfortunately, this appears to be fantasy, and they would need to be informed more about sickle cell disease.

“I wish to start worshiping again”

Psychosocial pain is closely related with spiritual pain, the effect of spiritual pain on the patients was described by the statement of a woman about 70years, who unfortunately died about 5days after the interview, she was receiving palliative care on account cancer, recurrent hypoglycemia, asthma and hypertension. Describing her spiritual pain and guilt she said:

“They (the church) have disassociated themselves from me because I don’t go to the church since I am sick, it has been a year now without attending services. So, they no longer count on me as their member. ... my heart is very willing but am not very fine, I wish to start worshiping again. The only fear I have is, if I delay, something might happen (i.e. die) based on how am falling sick. And I even confess ...my only known sin before God is local beer brewing. (participant 20)

A team member from the chaplaincy who is primarily responsible for taking care of spiritual pain and suffering of the patients enrolled in palliative care and in the hospital said

“Spiritually our patients are also affected because we believe if they are going to die they have to die with a belief ... like God has forgotten them, maybe God is punishing them, they have done something maybe God cannot forgive them. So, spiritually we want to support these patients not have spiritual pain where they feel they are neglected.”

Her pain was based on the experience of being left out of the church community and the feeling of having left God by action she felt was contrary to God’s law that she had engaged in. What the chaplain said is likewise reflected also in the stories of other patients.

While some religious institutions have been reported to be very supportive, others appear simply as business entities, the chaplain described cases where some churches have refused to help

“There are some churches too, whereby if a member does not give tithe, he’s not regarded as a member. But think of it, we are talking of a patient who is in pain; how can she get money, these are some of the areas that the church needs to scrutinize in helping the patients”

On the other hand, there are those who feel spiritually satisfied, for instance one of the patients felt so good and was coping very well, she was even very comfortable discussing about her death, saying she has prepared well for her death, which was quite unusual. The translator conveyed her words *“...the church is so supportive, they come to cheer me, to pray for me and I have no worries, no worries be it spiritual, psychological and I’m satisfied with my spiritual life.”* In this context, where it is generally not a cultural norm to speak about someone’s death, it was surprising that she was comfortable speaking about her death and even burial, this is because, according to her she was assured that her church would be there during her funeral and she would be welcomed in heaven.

Having presented aspects related to the life and living conditions of some of the patients registered with palliative care at Nkhoma, the narrative will continue with a description of how the team is organised along with the roles of individual providers as well as the scope of services provided, ranging from hospital to home care services.

Palliative care at Nkhoma

The Nkhoma palliative care team is comprised of hospital-based team and non-hospital-based team members. There are about 20 hospital-based team members, which include clinical staff such as nurses and non-clinical staff such as chaplain. Included in the hospital-based staff are clinical officer, nurses, medical assistant, agricultural extension workers, representatives from the pharmacy, representatives from the chaplain and social worker. The team has long lacked a social worker and the role of social worker was been taken care of by other team members, especially the chaplaincy. During my stay, discussions were ongoing about employing the services of a social worker. I left Nkhoma, a day before the planned resumption of a social worker. Although many individual health workers were attached to the team, palliative care was not their only or primary task at the hospital, the real situation was described by participant 3, a nurse in the team when he said: *“But the thing is that not everybody is working in the department full time., we are like seconding.”* This means that not all of them work fulltime with palliative care, even though they are members of the team, they serve like back-up and substitute when the coordinator is not available.

Apart from the hospital-based team, there is the non-hospital-based team comprised of trained community volunteers. There are about 20 of them scattered around the territory of Nkhoma hospital catchment area. Furthermore, the non-hospital based supportive team members include the village headmen, traditional healers and local religious leaders. For instance, 20 religious leaders were trained in 2017 and in 2018, training was done was about 114 traditional healers and village headmen to give them basic knowledge of palliative care and to facilitate their cooperation with the palliative care team. Although not part of the team, healthcare providers in the hospital have been sensitized to refer potential patients from their respective departments to the palliative care unit for possibly enrolment in the program.

The direct oversight of the program is in the hand of the coordinator who happens to be an experienced nurse, having worked for years at various departments at Nkhoma hospital. At the onset of the Nkhoma palliative care program, trainings and workshop were carried out for

healthcare personnel in the team, however, some started without any knowledge of palliative care but then advanced gradually, participant 4 said

“although I didn’t receive any training when I started but then I went for a week training, later I went for a training for about five weeks where I did initiator course in palliative care then my interest at least was increased. That’s when I thought to continue with bachelor’s degree in palliative care of Makerere university.”

The providers and their roles

The team is comprised of members from different disciplines working together to care for wellbeing of patients and their families. Some in the community have supportive roles and are not directly involved with the team.

The coordinator is a nurse who started coordinating the program in 2016, playing a central role in the team and this involves seeing most of the patients and their families with whom she believed she has got a good relationship. Efforts have since been made to ensure palliative care services are available within the hospital daily. Besides consultations with patients and their family, she added *“my main role is to see that the partnership (with sponsors) goes on, giving some reports, communicating with them.”* Thus, she relates with the sponsors, hospital management, fellow team members, palliative care associations and patients and relatives.

The clinical officer on the team, is actively involved in the palliative care, even though his primary place of assignment within the hospital is not the palliative care clinic. He participates in running the palliative care outpatient clinic within the hospital when necessary and regularly participates in the home-based care. He said

“I work hand in hand with the coordinator, like preparing the reports, attending the meetings but also following up the donors if they are delaying the funding of our program. Also, I am also playing a role of mentoring our staff here and those from other facilities.”

As of now we are having other facilities, about six, which we are mentoring as Nkhoma palliative care”

The nurses and medical assistant and others on the team participate in consultation with patients in the hospital, in addition they direct patients that might benefit from palliative care services from their respective departments to palliative care and review palliative care patients on admission in their respective wards. Some of them are less experienced, whereas other have more advanced training and experience.

The agricultural extension worker oversees the nutritional aspects, encouraging patients and their families to develop home vegetable garden. She *“carries out clinical and anthropometric measurements on the patients to see their malnutrition level using Malawian guidelines”* and determining what intervention is suitable either by giving *“‘Likuni phala’, this is flour, blended flour (maize and soybeans), to help fight the malnutrition... or Ready to Use Therapeutic Food in the form peanut.”*

A representative from the pharmacy who is also a team member believes that there is no palliative care without morphine – an opioid pain killer. She explained the importance of her work which included keeping drugs record, especially for controlled drugs such as Morphine, which is a regular drug used in the palliative care, pointing to the importance of being able to distinguish other patients from those under palliative care, not just because the latter gets drugs free, but also as she explained *“I have to cross check, ... is this patient really on palliative care, do they repeat patients’ names, before supply.”* This I understand is to mitigate dispensing excessive amounts of opioids.

Even though the chaplains do not carry out specific medical procedures, they believe they play a role in supporting the patients, especially those socially isolated and/or spiritually starved patients. While it is a collective role of the team, the chaplaincy at Nkhoma hospital look at the spiritual aspect, as it applies to palliative care. One participant said

“spiritually we want to support these patients so that they should not have spiritual pain where they feel they are neglected...also socially, we interact with the families because we

know they are unable to take care of themselves and most times the illness is for long. So, socially we interact with the family to see how they take care of the patient”.

The community volunteers serve as the eye of the department within their respective communities. At the same time, they are encouraged to search for new patient on behalf of the hospital personnel in the villages, which otherwise could just die without any help. One of them described part of their role, saying

“We are based in the community; the hospital gives the patients medication and we are supervising how they take the medication. We introduce ourselves to the patient, seek consent from the patient, ask them how they are feeling on that day, check on their review dates, how they are adhering to the medication, and then we report back to the hospital.”

On the other hand, traditional healers and village headmen are usually influential members of their community, even when not socioeconomically at an advantage. They pose unique challenge in that they claim to heal almost any illness, even those with known cure medically. They even admit these patients into their ward and may further harm, such as when they put tattoos and scarification marks in unsterile environment a participant explained. On the other hand, when the village headmen are well-informed, they may help refer or locate patients that might benefit from palliative care or ensure relatives do not abandon such patients. The program coordinator described it this way:

“...with traditional healers you know there is conflict of interest, in the hospital you would say the patient have this condition ...but then the traditional healer would say no, you have been bewitched by somebody, so, you should not take what the hospital says.”

An increasing trend was reported among some religious movements, who are trying to convince people that they can heal them, provided they pay. This has prompted the team to involve religious leaders, training them on how to help the patients without giving false hopes them. These ones are believed by some to be extortioners, capturing the vulnerable and desperate patients in their quest for cure After the training organised by Nkhoma hospital, some religious

leaders have been reported to be more cooperative with the team and are now better suited to provide psychosocial or spiritual support to patients.

Common cases requiring palliative care at Nkhoma hospital

The type of cases requiring palliative care may vary from one region to the other. The table below summarizes the common type of the cases requiring palliative cases at Nkhoma hospital catchment area and their prevalence.

As shown in Table 1, majority (55%) of patients enrolled have a form of cancer or the other. Cervical cancer is the most common disease in women registered for palliative care and the commonest reason for clinic visit. Liver Cirrhosis is the commonest diagnosis, this is associated with high prevalence of hepatitis infection in the community. Consequently, some patients present with signs and symptoms of portal hypertensions such as pedal oedema, abdominal distension, and bleeding oesophageal varices. About one in ten patients (11%) enrolled in palliative care are children (<15 years old). Sickle cell disease, Cancer and Congenital Heart Diseases are among the leading causes for child enrolment in palliative care at Nkhoma hospital.

Table 1. Distribution of registered cases at Nkhoma Hospital	
Liver Cirrhosis	25%
HIV/AIDS and Kaposi Sarcoma	21%
Cervical Cancer	19%
Other Cancers e.g. Esophageal	15%
Other diseases e.g. Tuberculosis	20%
Cancers (in general)	55%
Liver Cirrhosis	25%
Other diseases	20%
Adults (>15 years)	89%
Children (<15 years)	11%

A significant number of patients have multiple diagnosis. For example, a hypertensive patient might be diagnosed with Cervical cancer, HIV/AIDS and Tuberculosis (TB).

How many patients are currently benefitting?

“In terms of enrolment of patient, the number has been increasing but the problem is you can’t give a certain number because in the process many patients dies.” the coordinator said. As at the time of data collection, the team has about 130 registered patients, but as explained the number is very dynamic. These patients were diagnosed with advanced cervical cancer, end stage HIV/Kaposi sarcoma, liver cirrhosis and cancer of the breast, among others. Children make up about one in ten of the registered cases with chronic and life-limiting conditions such as sickle cell and congenital heart diseases.

The number of hospitalized patients vary from time to time, this presents a unique challenge since identifying these patients and instituting care plans needs to be in collaboration with the admitting department. This may be because the palliative care unit does not have a dedicated doctor trained in palliative care. The admitting department often sends message to the palliative care unit, and then a ward round is done to visit the patients. Relapse and deterioration are not uncommon in admitted patients. Besides prescribing medications, there are instances that requires non-pharmacological treatment to relieve pain, procedures such as abdominal fluid tapping and colostomy. Such procedures are carried out within the hospital or at times in the villages during home visits at the residence of the patient *“So, all of us in the team except for the chaplaincies is able to do abdominal tapping”*. Sometimes when a patient is on admission the staff members in the departments could also help perform the procedure and then report back to the palliative care about which procedure were carried out, thus collaborating with one another.

Organization of Nkhoma palliative care services

According to the coordinator the Nkhoma palliative care project has two models of palliative care, namely, hospital-based model and home-based/community model.

The first model is the hospital-based care, this usually involves consultations with patients from 8:00am to about 4:00pm, Monday through Friday in the palliative care clinic for outpatients and reviewing inpatients cases on admission. Patients come from the catchment area and beyond, to the hospital, some of the patients are already enrolled in the program, whereas others are newly referred from various departments in the hospital or from the ongoing cancer screening program within the hospital. Those diagnosed for instance with advanced cervical cancer are enrolled in the palliative care program. Since most members of the team primarily work in other departments, the schedule for clinic consultations is often not followed. Apparently, other care providers run the clinic typically when the coordinator is absent or busy elsewhere.

The second model is the home-based care model where the team normally go for home visits two days in a week on Tuesdays and Thursdays, provided there is enough resources to fuel the ambulance. One of the hospital-based team members summed it up as:

“a team of about four; the nurse, the clinical officer or the doctor and the driver and one of the chaplaincy members going together to visit the patient depending on the need of that patient and offer holistic care to the patient in the village.”(participant 4).

The community-based model is not fully established at the moment due to drug policy restricting community health centres – typically, the centre of community-based palliative care, from storing or dispensing opioids such as morphine to patients in need. However, the team draws on resources in the community, such as trained community volunteers, in service delivery. It is likely for this reason that some participants use the term home-based care interchangeably with community-based care. Since the health centres in the communities have this limitation, any patients that they feel might benefit from palliative care services are usually referred to Nkhoma mission hospital for comprehensive palliative care.

Comprehensive palliative care - Nkhoma holistic approach

Nearly all the providers that participated in the interview described the palliative care provided at Nkhoma as 'holistic'- this was a recurring expression throughout the interviews. For instance, participant 4 explained it this way:

“Basically, for all the palliative care patients, the normal approach is taken and that is holistic approach. So, when the patient is admitted who has got life threatening illness, and this is a palliative care client, then he is approached holistically. So, you are looking at the physical, the social, the spiritual as well as the psychological. When they are in the hospital, the chaplaincy will be visiting them, when they have got pain, we need to do the pain scoring, when they have got social issues, we take care of the social issues, when psychological, we also take care of the psychological. Aside from that, then also the actual problem the patient has come in with.”

See Table 2 for components of Nkhoma palliative care services. Elements of this include the provision of relieve from pain and other distressing physical symptoms, mentioned by patients during the interview such pain, exhaustion, difficulty breathing, recurrent bleeding, nausea, dizziness, loss of appetite, abdominal distension, vaginal discharge and vomiting. The team continue to use pharmacological and nutrition therapy, so that patients can feel as best as they physically can while they are still alive. Although physical pain was referred to as a major problem that demanded close follow up, patients present to the hospital and palliative clinic with more than just the physical symptoms.

“They come with little physical pain but huge psychological and social pains”

A participant noted that there are several patients that come with little physical pain but a whirlwind emotional and social suffering related to poverty, fear, anxiety, helplessness, social withdrawal, self-pity, abandonment, peer rejection, intense feeling of guilt, anger, depression,

worthlessness, stigmatization, and loneliness. *"...and they come with little physical pain but huge psychological pains, social pains"* participant 1 said. Family members, guardians and at times the community get exhausted. The hospital based and community-based team members tries to provide both parties resources for managing their stresses and emotions. They often connect the patient and family to additional resources through counselling, support groups in their community, or make referrals to mental health professionals whose office borders the palliative care clinic, if needed. The palliative care team works with the chaplaincy to assist patients and their families come to terms with their illness and offer spiritual guidance and support. A chaplain observed that some patients desire to deepen their spirituality, others need support through encouragement and reassurance. *"...we encourage and teach them that it (the disease) is not a punishment from God... we normally encourage our clients to be in good relationship with God. The book of Isaiah tells us that even if our sins are like blood, God can make them white as snow."*

The team also looks at logistical issues since the stress and anxiety associated with chronic illnesses often make it difficult for the patients and their families to adequately plan logistical concerns. The team sometimes provide the necessary support in terms of preparation for death and plans for who takes responsibility of looking after young children of the patients after their death. This conversation however is not always easy to initiate. This challenge was described by a nurse, participant 10

"when you talk of end of life care and bereavement, western societies consider that as part and parcel of their life. But now when it comes to our set up, it's a thing that we are doing but still the outcome is not that desirable, because for somebody to talk about death when somebody is critically ill is like you are trying to foretell that somebody is dying. But when you start discussing this right away at the time the diagnosis was made, not that saying you are going to die tomorrow but you try to explain to the patient that we don't expect you to get healed..."

On the other hand, when patients and guardians perceive they have been well cared for in all aspect, they feel like one of the patients, diagnosed with bladder/cervical cancer, who was moved to say:

“...this is my hospital even if I die here, it will be nature taking its action, I will die here since I have visited a number of hospitals and am done. But here they always give us a warm welcome, it is a special case here, whether we come at night, any time, and the drugs they give is massive.” Participant 11

The caregiver of the above patient, who is the daughter added: *“am happy that they always give us a warm welcome when mum falls sick, but we used to struggle in these other hospitals before we came here, imagine!” Participant 11B*

The table below provides a summary of some component of palliative care services at Nkhoma hospital, these include physical, psychosocial, spiritual, and logistical concerns.

Table 2. Components of Nkhoma palliative care services	
Physical care	
<ul style="list-style-type: none"> ▪ Pain 	<ul style="list-style-type: none"> ▪ Respiratory symptoms (Cough, dyspnea)
<ul style="list-style-type: none"> ▪ Abdominal distension and fluid drainage 	<ul style="list-style-type: none"> ▪ Anemia
<ul style="list-style-type: none"> ▪ Vaginal discharges 	<ul style="list-style-type: none"> ▪ Skin lesions (e.g.in Kaposi sarcoma)
<ul style="list-style-type: none"> ▪ Recurrent vaginal bleeding 	<ul style="list-style-type: none"> ▪ Fatigue
<ul style="list-style-type: none"> ▪ Gastrointestinal disorders (diarrhea, constipation) 	
Psychosocial and Spiritual care	
<ul style="list-style-type: none"> ▪ Emotional distress 	<ul style="list-style-type: none"> ▪ Bereavement support
<ul style="list-style-type: none"> ▪ Fear and Anxiety 	<ul style="list-style-type: none"> ▪ Spiritual needs
<ul style="list-style-type: none"> ▪ Patient and caregiver suffering 	<ul style="list-style-type: none"> ▪ Depression and helpless feeling
<ul style="list-style-type: none"> ▪ Nutritional support 	
Care planning and communication issues	
<ul style="list-style-type: none"> ▪ Ensures drug availability (esp. opioids) 	<ul style="list-style-type: none"> ▪ Communicate with stakeholders
<ul style="list-style-type: none"> ▪ Network with sponsors 	
<ul style="list-style-type: none"> ▪ Facilitates community participation 	

The Hospital-based care

Most of the palliative care services carried out in the hospital is done at the palliative care outpatients' clinic. Patients receiving palliative care that require admission are usually sent to the ward that is most consistent with their symptom. For example, a patient with complications arising as a result of Liver cirrhosis might be sent to the Medical ward for admission, whereas a woman with recurrent bleeding might be admitted into the Gynecology ward. In such cases, the palliative care team collaborates with the admitting department to manage the patient. Patients may also visit the chaplain department within the hospital premises or at times, when patients find it difficult to move around the hospital, the chaplain comes to visit them in the outpatient clinic.

The outpatient palliative care clinic

At the moment of this write up, within the premises of the hospital is a small office arena used as the palliative care clinic. The clinic is equipped with two tables and four chairs, an examination couch, a small shelf for storage of drugs and other medical supplies and a printer. The 'one room department' receives several patients daily. Often patients come accompanied by their guardians and relatives. Three of the four chairs are reserved for the service providers while one is for the patient. At times, extra chairs are brought into the room for the patient's guardian or relatives, thus, making the room extra cramped. At other times though, the team members on the other table are coerced to leave the room to give chairs to patient's relatives. The room becomes more cramped with other guests in the room such as researchers, students and those visiting the clinic. Participant 1 explained that: *"when the patient is to be examined by medical personnel, or when the patient wants to explain confidential issues, we have to give each other space. Just that way...we have to move out."*

An average of 4-5 people are usually in the small room, as a result, during my first few weeks in the clinic, sometimes, I deliberately leave the office door open for cross ventilation, but I perceive that some were more used to having it closed, more than often the door get closed

after a few moment later. Thus, I regularly took a stroll to catch a breath. This challenge is not limited to those within the office. Other team members, for instance the chaplain expressed similar concern. *“At the same time, we have talked of the issue of infrastructure whereby the room which we are using as our clinic is too small and we normally fail to help the client in four angles I said.”* A nurse in the team said:

“We have a small room where we are using for consultation of the patients. At the same time, we don’t have a ward for these patients, because when a woman with advanced cervical cancer and bad smell comes in and is admitted in the ward together with other patients, this gives a lot of challenges to the woman and others, it would have been much better if we could have a small room for our patients.”

The problem with a small office space is not new to the palliative care team, participant 4 said: *“In fact, the room which we are using now has been donated by the hospital management because we had a very tiny room at first. In fact, at first, we had no room.”*

Palliative care services are available within the hospital between to 8:00-16:00, Monday to Friday. As such, patients requiring palliative care services who arrive after the clinic closing hours or during weekend either have to return home or get admitted to the wards depending on the severity of the conditions. Thus, needed care is provided by attending physician or clinical officer, and a consult would normally be sent to the palliative care team the next working day. Consultations with most patients and the guardian may take up to 30mins to an hour or more. Some patients require a more extensive care e.g. drainage of ascitic fluid in patients with liver cirrhosis, and some may require admission.

On selected days in the hospital, a sort of debrief occurs. More than once during this general morning reports, some have raised questions about cases to refer to palliative care. For a number of clinical staff identifying who can rightly benefit from palliative care services is not so easy. This might be the situation because, from my observation, a significant proportion of patients in the hospital have an overwhelming social and psychological needs, in addition to the physical symptoms they are presenting with, in taking care of the physical pain, participant 6 said:

“...it depends (on the severity on the pain), for severe pain, we use morphine, the one that is mostly available in Malawi. But the other pain, we use WHO analgesic ladder we start with non-opioids then we go to ladder number three then we use morphine.”

Speaking about the morphine given to the patients, a representative from the pharmacy in the team said “We get the already constituted one, the central medical store does that and pack it in five-litre bottles. The image below is an example of the opioid analgesic form typical prescribed and dispensed at Nkhoma hospital.



Figure 3: Liquid Morphine dispensed to a patient at Nkhoma hospital, picture taken within the palliative care clinic. In the background, on the wall is the analgesic ladder, for drugs to take care

of mild to severe pain. Patients are usually expected to return to the hospital for refill before exhaustion, at other times the drugs are taken along during home-visits.

One challenge mentioned is the absence of a dedicated ward for palliative care for observation and/or admission. As a result, patients in palliative care often have more than one case file in the hospital. Since a separate file is used in the ward, could problems such as fragmentation, coordination, and errors such as double dosage and polypharmacy - which is the concurrent use of multiple medications by a patient arise as a result that. One participant believed that having a palliative team member in the different departments who can crosscheck the new prescription, might be the reason it has not really been a problem. He said:

“Basically when it comes to the files, the files which the palliative care has in the clinic are completed differently from the ones in the wards, most of the members of staff who are working in the palliative care come from different departments of the hospital...So, these team members are also consulted within their department.....”

Identifying who can benefit from palliative care

One main barrier to palliative care delivery is locating patients who need the care but are dispersed in the villages in the rural communities where the majority of patients are without access to health care in general nor palliative care. In addition, a large proportion of patients presenting to the hospital with chronic or life-limiting illnesses need palliative care. Many patients live far away in remote territories miles from the hospital and some had never visited the hospital in their lifetime. Even though the services are available, it is important to get those that really need it to utilize it. Participant 3 described what the initial routine is when a new patient arrives at the department, he said:

“When the patient comes to our clinic, we have to verify that is this confirmed that is a case of any sort of cancer (or cases requiring palliative care). When we have an answer - yes, then we have to open a file specifically for palliative care.”

The file is divided into sections recording the biodata, presenting complaints, diagnosis and history of illness. It is further divided into parts that requires information about physical, psychosocial and spiritual aspects of life. Noteworthy though that not all patients remain enrolled for life. He continued, “...we enrol the patient but in due course we if find out that has no signs for palliative care wheel, we are supposed to discharge the patient from the palliative care program.”

Identifying who can benefit within the hospital

An important portal through which patients are recruited is the hospital. When patients with chronic or life-limiting health challenges present to the hospital, these are treated and thereafter referred or discharged through the palliative care clinic.

The ongoing cancer screening in the hospital, invariably identifies patients with cancer and especially those in advanced stages. Others are sent directly to the palliative care clinic after testing positive for HIV in the HIV clinic. One of the participants described the role of the out-patient department in recruiting patients saying

“...we trap them there, some of them are referred from their places. When we see those patients, we send them to palliative care clinic, so they are registered. When we identify a palliative care patient from departments or referrals from other areas, then these patients are also enrolled in the program.” Participant 7

At other times, the different departments within the hospital send consult to the team to visit a patient on admission, although lapses exist such as those described by participant 4:

“...(But) sometimes it happens that the person who is working in the department doesn't have proper knowledge on how palliative care works. Because of the staff turn-over, sometimes there are new staff who are coming. Some of them are coming in the department just for part time for locum because of the shortages of the nurses and other

health care worker providers. So, under such circumstances, some patients are forgotten to be reported to the department”

Identifying who can benefit from neighbouring health centres

Nkhoma hospital serve as a referral centre for a number of health centres in its proximity. These health units are usually without doctors, they rely only on the services of a nurse and of medical assistant. Despite not being able to provide first-hand palliative care services, Participant 3 explained their role, saying:

“Other health centers often refer the patient to Nkhoma hospital but if the patient may not be able to walk, then they send us a message and we have got ambulance specific for that then we could send the driver and pick the patient to bring to Nkhoma. Then we see the patient in the hospital. In Malawi is very difficult to have palliative care at the health centre, but we train them at least to identify palliative care patients. In Malawi a health centre is not allowed to keep morphine. But in palliative care we say: ‘palliative care minus morphine is not palliative care.’”

Additionally, there are cases from tertiary hospitals such as Kamuzu Central hospital (KCH) located in Lilongwe, because of proximity of the patients to Nkhoma hospital. Others come to take advantage of the free services at Nkhoma palliative care clinic because *“it’s possible that where they are coming from, they pay for services, but here at Nkhoma they don’t pay.”* Participant 7

From the community - *“The volunteers in the community come to the hospital to tell us.”*

Apart from the departments within the hospital and health centres within the hospital’s catchment area, the coordinator explained that the meeting and trainings they had with the community support systems which include the community volunteers, traditional healers and religious leaders is serving a good purpose in helping locate and enrol patients from the communities and villages. She said it acted as one of the ways of sensitizing the community about palliative care since there

exist very sick patients who are either unaware of palliative care services or cannot come to the hospital by themselves.

“What we normally do is like we have established a system where we’ve got community volunteers in palliative care, the chiefs around the area have been oriented on palliative care. So, within the village set up, there are people out there who are also working hand in hand with us. We are assisted through the funds from the collaborating partners in Norway. We have purchased cell phones for the guardians in the village and the volunteers in the villages. So, if the patient has got any problem, then follow up is done by a volunteer in the village who is able to communicate with the members of the team ...” Participant 4

How are follow ups done?

The chronic nature of illnesses requiring palliative care at the department coupled with the long distances travelled by patients before getting to the hospital requires a good follow up system to ensure continuity of care. Follow ups is no easy task more especially in the rural settings with limited resources. Generally, patients that are attended to in the clinic are appointments to return while patient met during home visits are invited or taken to come to the hospital.

Circumstances are not always favourable both for the patients and the departments to do follow ups. Many patients are unable to return to the hospital because of the financial implications of the journey, long distance to the hospital and the need to have someone to go with them because they are too weak to travel alone. Similarly, the palliative care department at times face difficulties locating patients address in rural areas. This is because often houses in the rural communities are often not well marked, or not marked. As such, the only address given by the patient is the village and his or her name known to the community. Several patients live far away (>20km) from the hospital, with untarred rough roads. At other times the community volunteers do follow up patients and report back to the hospital when the hospital team is unable to visit.

Participant 6 who organizes the follow up at home explained that it:

“is usually supposed to be after three months. Maybe I should say at first when I am doing monthly report for those patients that have given me the phone number, then I am able to call... Other way is when you see three months patient is not coming (we take that patient as inactive patient). So, we arrange for routine visit to their homes to see what is happening to the patient.”

Generally, there are several ways patients leave Nkhoma palliative care program. One way is when the patient dies or are lost to follow up, perhaps because the patient relocated. Others are discharged home, for instance a patient who has been cured of Tuberculosis. Referrals occur especially when patients need specialists care or when management modalities are not available at Nkhoma. Participant 6 commented that *“we’ve...just be referring patient to get chemotherapy for ... , if those services were available here, we could have so many people managing locally, but they are transferred”* possibly using the department’s ambulance to the central hospital at Lilongwe, and eventually such patients are lost to follow up..

The Home-based care

An integral part of the services provided is the home-based care. It involves visiting the patients in their natural environment to provide physical, psychosocial and spiritual care. The visit gives the care providers insights into needs and challenges of the patients, thus helping to improve services delivery. Prior to the visit, the team decides who to visit and anticipates the needs of the patients to be visited. Members in the team take turns to visit patients in their homes navigating through dusty roads along the undulating terrain in the mountainous regions which may span several kilometres away from the hospital. The initial visit may involve stopping several times along the route to ask for direction this is because addresses are not clearly marked in rural communities and locating the houses might be challenging. After deciding who to visit, the ambulance driver is notified, and team members informed. Also, a representative from the chaplain usually join the

visit to provide spiritual support to the patients and their family, this may simply involve offering a heartfelt prayer with the family. The agricultural extension working under the *Chifundo project*, may also use this opportunity to carry out nutritional assessment and encourage patient and their relatives to have a small garden of vegetable at home. A participant describes what happens at the homes of the patients:

“when we visit them, we chat with them, we ask their problems, we ask how are they cared by their guardians, are they caring them, are they taking care for them, are they providing food to them, all those things? We ask them how they are getting drugs. We ask them how they are coping with drugs, new complaints.” Participant 7

I was able to join a number of home visits, with an average of about 5 individuals in the ambulance, the team sets out on a journey that may take up to 5 hours before getting back to the hospital. Many patients live several kilometres away from the hospital in rural communities far from tarred roads. Even though the visits are usually not pre-arranged with the patients, still we are warmly welcomed and not seen as intruding. While some of the patients are bedridden, others are still ambulatory and can still carry out their daily routine normally. It is possible not to find a patient at home after travelling such a long distance. This was the case with a participant 11, who we did not meet at home, only to be informed by her children that she has gone to the hospital, where she was placed on admission in the female medical ward.

Majority of patients in those communities lack basic social amenities. Furniture is a luxury that most cannot afford, so, it is not uncommon to sit on the floor around the patients during such visits. The visit that may last about an hour typically starts with exchange of pleasantries, followed by discussions about the patients' health and wellbeing. The discussion typically centres around control of physical symptoms such as pain management, psychological issues like community perception of patient's illness, discrimination or isolation as a result of factors such as offensive smell, in a patient with cervical cancer with discharges. During such discussions one cannot but notice and talk about the socioeconomic challenges, many in those communities are severely affected by poverty. Some do not have access to clean water, others are restricted to eating only

one type of food which is maize, with little and most often no added protein. Consequently, many appear chronically malnourished.

“...We find patients homeless, others without beddings, others without food yet they are taking medication. They really struggle. They are in pain. They have stopped doing their businesses and working as before (because of illness). They have been sick for several years and the only hope for them is the hospital. So, we really feel sorry for them” Participant 1

The picture below was taken during one of our visits to the homes of patients, after a long journey.



Figure 4: Visit to the home of one of the patients living in a mud house with grass thatched roof. Unfortunately, the patient had gone to the hospital and we met only the children at home, who were hungry.

The team go along with medical supplies such as gloves, disinfectants, liquid morphine, Bisacodyl tablets (laxative prescribed along with morphine to counteract the constipation that may result from the use of morphine) and other supplies. Depending on the availability of resources, patients may in addition to medications refill, received some basic social support such as foodstuffs, soap, blankets and beddings and so on. Procedures may be right in the home of patients. An example was given by participant 4 below:

“When you go to the village for home visits, you find patients who have got huge ascites then we do the tapping there. So, each one of us in the team except for the chaplaincies, the chaplaincy is able to do abdominal tapping.”

Care recipients report that they value the home-based palliative care in many situations. For example, many patients are more comfortable at home than in a typical clinic setting, also it safes them the stress and cost of transportation. Furthermore, I observed that family members are more easily informed and integrated into the care during home-based. A home-based approach provides advice and support to family members to help them as caregivers. On one hand, it helps increase community awareness of palliative care, thus mobilizing local resources and support networks. They appreciate the social benefits and enjoy having people from the hospital to speak with, which is both a source of relieve and comfort. *Participant 20* said *“I know that your frequent visits will keep bringing me more happiness as it is now.”*

Another patient who was diagnosed of cancer of cervix said:

“They told me I was late, and they couldn’t operate me since the cancer had spread to other parts of my body. They then referred me to palliative care. They have greatly helped me, because the symptoms I had in February, a year before last year, have all gone”
Participant 4

Such visits do not go unnoticed by neighbours in the community who apparently would like the prestige of being visited even though they are not sick. It is no surprise that quite a number of people in the community gather around the house of the patient while we were inside. On the other hand, a patient mentioned that the visits sparked rumours in her community on a few

occasions, that she was dead, and the ambulance has come to remove her corpse. *“I know the community wished I am dead, they will rest, many times they have carried rumour that I have died.”* Nonetheless, she is not negatively affected by such rumours, on the contrary she looks forward to subsequent visits, she said:

“I feel very happy. You are like my relatives, even though people in my community wish that I am dead. Besides the free treatment, they also give me soap, food supplements, cooking oil to mention few, I take them as my relatives, they are more than my relatives by blood, they are caring for me so much.” Participant 18

Some providers commented that since they go extra miles, not only in terms of distance, to provide support especially during home visits, restoring an initial compensation scheme would be appropriate to sustain their motivation. Although the team would like to expand its home-based care in terms of coverage and frequency, it is often limited by resources resulting in trips being cancelled because there was no money to fuel the ambulance.

“when we run out of funds, then we don’t have money to purchase gas, diesel for the ambulance and that brings a problem to us. Like right now, we don’t have money to purchase diesel and we are not be able to have enough visits to the patients because of that” Participant 4

It was a privilege to be with the team during a dry season, this made home visits a bit easier as it turns out to be more challenging when the season changes:

“...very far, and during the rainy season there is big problem. Sometimes when you want to visit the patient, the ambulance could not manage to reach the to the house of the palliative care patient. But sometimes ... the palliative care team have to walk up to the area, a shorter distance.” Participant 4

Such seasonal changes affecting transportation along with other factors such as finance and patients’ comfort were cited by some as reasons to have the drugs closer to the patients in the community health centres, rather than just at central and district hospitals like Nkhoma. He

continued: *“if I were in a position to decide I would exactly allow health centres to keep the morphine, because we have seen how patients are struggling to get to Nkhoma hospital”* instead of receiving a community-based care.

Establishing Community-based palliative care

The Nkhoma community palliative care is still developing. Typically, a community health centre (CHC) is the centre where community-based palliative care services are offered and usually such services are run with participation of members of the community. The Nkhoma palliative care project recruit people in the community to participate in solving their own problems. The project, through Norwegian partners have trained community members such as village headmen, traditional healers, religious leaders and community volunteers.

“...mainly the Norwegians come to assist us with training. They organize money, funds for training religious leaders, health care volunteers even the traditional healers. The chiefs are also supported by the Norwegians.”

Inability of the community health centres (CHC) to participate directly in palliative care, because of regulations restricting opioid storage at such centres, has been cited by some participants as a limitation to the community-based palliative care:

“when it comes to ... morphine they expect that to be done at district hospital like Nkhoma, KCH but then you see that these big hospitals are very far from our patients. Most of them are relying on what we call health centres, these are health units where we will have a nurse and also a medical assistant. So, this has been a challenge. It has been a challenge because currently, we are not legally allowed to give morphine in such small health units.” Participant 10

Although, the health centres are unable to provide first-hand palliative care services, the purpose of training those health care workers and the community members was justified by a participant who said:

“Other health centres often refer the patient to Nkhoma hospital ... In Malawi is very difficult to have palliative care at the health centre, but we train them at least to identify palliative care patients. In Malawi a health centre is not allowed to keep morphine. But in palliative care we say: ‘palliative care minus morphine is not palliative care.’” Participant 3

Explaining the purpose of the traditional healers the coordinator said they can identify patient and refer them for palliative care. This is *“so that people don’t misinterpret the patients as been bewitched... but also traditionally there are other herbals which patient are allowed to use such as ‘moringa’ and the ‘baobab’ used for anaemia, which those traditional healer can as well give to our patients.”* The village headmen and chiefs have a measure of authority in the community, so they are important in settling family quarrels or can intervene when a patient is abandoned. For instance:

“We went through the chief yesterday, we sat with the family and then later we discussed the issue and say no, together we can work and assist the one who is suffering because if people are divided, the sufferer will still be the patient because nobody would support that patient.” Participant 6

Training the community volunteers and others was said to be a means of sensitizing the community about palliative care and mobilizing local resources. This was explained:

“So, within the village set up, there are people out there who are also working hand in hand with us. We are assisted through the funds from the collaborating partners in Norway. We have purchased cell phones for the guardians in the village and the volunteers in the villages. So, if the patient has got any problem, then follow up is done by a volunteer in the village who is able to communicate with the members of the team ...” Participant 4

The pharmacy acknowledged the rise in the number of patients registered with palliative care and this increase has also been accompanied by an upward trend in opioid consumption. This development calls for more scrutiny from the pharmacy. A representative from there said: *“In the past we used to have four jars of five litres lasting for two months and we later increased of five. So, the five that we increased is the one that just ended within the short period in the last month.”*

Moreover, I interrogated team members about cases of opioid abuse or misuse within the team or by patients and their families, they told me so far its unheard of, a nurse explained that with his 5-6 years of experience with controlled drugs, he has not come across any such case. He explained:

“I feel it’s some of the myths that people have. When you mention morphine, people associate it with addiction, but... I have learnt that it is a thing that is in the minds of people but practically I have never seen such situations.” Participant 10

The positive impact of the community volunteers was recalled by a family whom they helped and directed to palliative care on account of chronic pain. The father explained:

“we were approached by a palliative care community volunteer who advised us and directed us to come to this room (palliative outpatient clinic) to meet doctors.” Participant 19B

Funding for the palliative care services at Nkhoma

Health insurances are typically non-existent for the patients and majority of them along with their family are poor and as such cannot afford basic healthcare. Payment for palliative care services come from different sources and the department rely on multiple sources to ensure the smooth

running of the program. One is through the government: *“and the other partners include the Ministry of health and Palliative Care Association of Malawi, PACAM”*. Participant 4 speculated that the government, provides a maximum of seven thousand Malawian kwacha for each patient per month and then continued:

“So, if the patient’s bill is less than the seven thousand its ok, but if the patient exceed the seven thousand, he has to pay. But in case the patients cannot afford it. We would not like to refuse the services to the patient, we have to give. But the one to suffer is the hospital.”

He admitted that it may become a challenge to determine whom to provide the aid, as it may not be apparent who truly cannot afford the bills. Ultimately, the hospital bears the burden and struggles to release fund he said.

The role of foreign support in funding and training at Nkhoma

International organization and Non-Governmental Organizations play important roles in ensuring the continuous and proper functioning of the Nkhoma palliative care program.

“At first, we had the EMMS International from Scotland through a program called ‘Methods’. They were sponsoring us, but at the mean time they stopped paying for the funds and the hospital is struggling on that. But now there is another program through the same EMMS, now they are focusing on nutrition. They are teaching the Agriculturists to be taking care of palliative care patients.”

In a low-income country like Malawi, where palliative care services are still developing and awareness is patchy, there is a role for overseas support in training as explained by participant 6

“Our hospital depends on the donors. Our main donors are from the UKAID and this is maybe around fifth year that they have been supporting the services of the palliative care. The other donors are from Norway also and Bergen they are also our partners. Mainly the Norwegians come to assist us in training. They organize money, funds for training religious leaders, health care, volunteers even the traditional healers. So, those training are normally funded by people from Norway. The chiefs are also supported by the Norwegian. And then

we have got a third partner from the US; hospice of the north coast. They are also our collaborative partner”.

Apart from European sponsors, there are sponsors from the United States, who are also supporting the palliative care project at Nkhoma. Participant 4 added

“And we also have another partner in the US, Hospice of North Coast. Hospice of the North Coast has helped in the sponsorship for my scholarship for my bachelor’s degree in Uganda and they have also helped us in recruitment of the social worker. So, very soon we are going to have a social worker who will be working with the team.” Participant 4

In order to expand and sustain the palliative care services provided free of charge, it was opined that engaging more stakeholders or sponsors who are willing to cover other aspects of the program will go a long way in helping the team and ease patients living a life of pain and suffering.

Gaps and barriers of the Nkhoma palliative care program

There are several positive developments since the inception of the palliative care program in 2015, that were pointed to during the interviews and other latent discussions with team members. Notwithstanding, gaps and barriers too, have limited service delivery. Some of these are internal, that is, factors within the team, others are external factors that affect the palliative care services.

Tensions and latent conflicts within the team

During the interview, some participants were asked about the harmony, tensions and latent conflicts between team members that have significant impact on patients’ care. While some might have hesitated to disclose interpersonal issues during the interview, others however, commented freely about tensions and how they were integrated into the team. Although many

in the team shared similar thoughts with participants 7 who said: *the relationship between us in this program is so good, we are working together as one.*” Some participants pointed out gaps. One is about attendance at the team meetings and the other is about pharmacy integration. Generally, the team is expected to have weekly meetings which serve as an avenue to bring the team together to discuss challenges within the project and to provide feedbacks as well as to plan the way forward. After my arrival, I was introduced to the team during such meeting and thereafter I attended on a few occasions. However, being able to hold the meetings as scheduled and having most team members attend is an on-going struggle. Explaining the implication of that, participant 10 said:

“we are failing to have regular project team meetings for the same reasons that I have said..., if we agree to meet on Wednesday afternoon, then you are in the wards with patients to be admitted, you cannot abandon your department; obviously you say ‘guys my apologies I will not make it (to the meeting)’. So, at times we have planned meetings and we have failed, that alone has also been a challenge because such meetings are very important as you share experiences, if it’s a meeting to be attended by 15 people, you only have 5 or 6 of them, you don’t expect something good from that because the majority are not with you and probably they would not even get the issue you were discussing as a team, that also affect the quality of care that you give the patients”

Another team member from the pharmacy complained about poor integration of the pharmacy into the team, especially during home-visits. While other team members did not report having to deal incomplete sense of belonging, the pharmacy at some point felt poorly integrated based on the comments from a representative from the pharmacy:

“I can say at first when the members were increasing, we had to adjust...they were operating separately without directly involving the pharmacy... Then you could see a lot of people prescribing for palliative care patients without knowing who is in the team...until when we approached them to say ...‘you have to involve us so that we can manage well on our ordering systems’. So, we pleaded with them saying there is a concern that we

have about involving pharmacy in your home visits. But then, there hasn't been a reaction from that side... Now they have improved but our primary concern is that we have to be joining them when they are doing their home visits...because that's where you can find most of the information."

Having team members come together to give feedbacks, discuss challenges and find solutions has been an ongoing struggle for all but especially for the coordinator. In addition, the pharmacy they have not been adequately integrated into the team and home-visits. Factor like these hinder information flow within the team and may affect the quality of care given to the patients.

In addition to internal factors, several external factors significantly limit the palliative care services, these are explained and summarized in the chart below

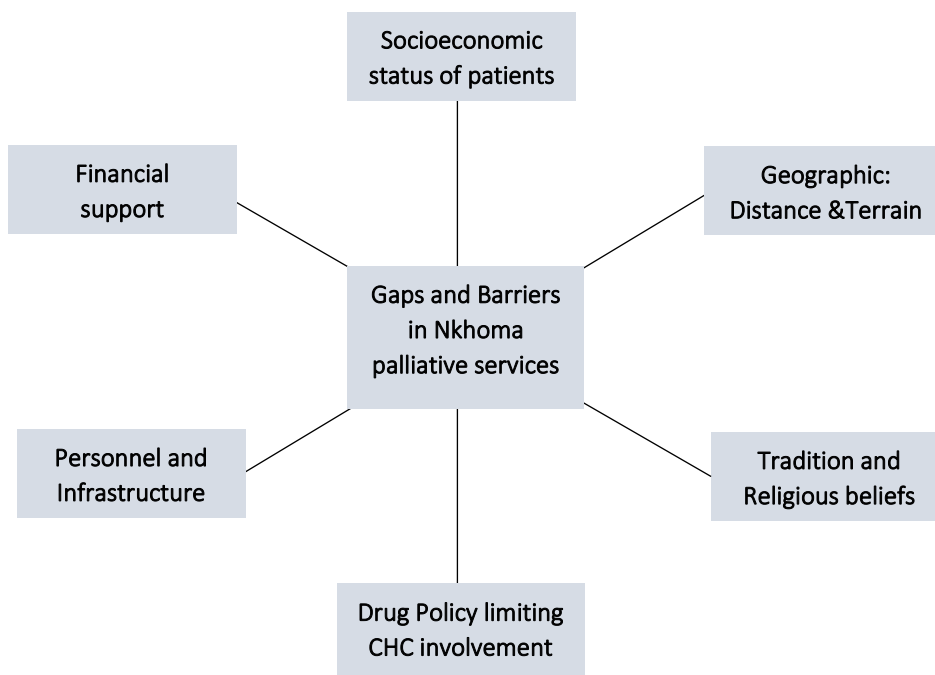


Figure 5: Main gaps and barriers identified with Nkhoma palliative care services. CHC: community health centers

Drug policy affecting palliative care

There is quite a controversy about the policy restricting storage of opioid pain killers in the community health centres. Some arguing in favour of lifting the restriction while others believe such restrictions are necessary. A participant noted that health policy must take into consideration the scarcity of resources and the unique needs of its patients. He said:

“If this morphine is taken close to where our clients are staying, I think somebody would take two to three hours walking slowly to go and fetch it. By the end of the day the (guardian or patient) should be able to get it unlike covering 20 to 30 kilometres.”
(participant 10)

He believed taking morphine closer to patient would mean easing legislation restricting storage of morphine in the community health centres as these units are closer to most patients who cannot afford to pay for the cost of transportation to Nkhoma hospital. On the other hand, some decide to walk to the hospital, this is not an easy journey for anybody especially giving the terrain, that may require ascending or descending hilly landscapes. It is no surprise then that even healthy relatives will find it difficult walking kilometres to the hospital to get the drugs in behalf of the patients.

Another participant who believed that the argument could go both ways said: *“we are having the ART program which is giving Codeine in health centres for ART patients.”* This participant implied that codeine is an opioid medication with similar characteristics with morphine, and it is supplied to the health centre for ART clinic. Thus, allowing codeine and not allowing morphine for palliative care sounds absurd. Moreover, she added:

“I think it’s not good to have those medications at the health centres because of some side effects...I think there is no one to cross check with them. Because maybe you can just medical assistant and the nurse. There are two of them, if they decide to misuse the product, it’s easy rather than here you have some people surrounding you. So, I think it’s really good keeping Morphine, the Codeine and all the opioids in a facility where they can be handled other than in health centres.” Participant 5

Financial, Psychological and social barriers

Life-threatening illness have serious financial impact on the patients at Nkhoma, who have to pay out-of-pockets. Poverty is endemic in the region, this alone cause much physical and psychological pain. The social needs of the patients are huge, even though they are the very basic needs such as food, shelter and healthcare. Most of the patients were unable to feed thrice or twice a day, in fact some go hungry for days. For most of the residents in the villages, food is simply the mixture of ground maize mixed with hot water, while house is a very small structure made of mud and covered on top with dried grass as a form of roof. It is not hard to picture why these patients may be hesitant to seek healthcare in the hospital. Eliminating the financial implication of treatment is one good to alleviate access barrier and this is what the Nkhoma palliative care is trying to achieve. However, there is a significant gap in the apparently free services provided. This gap is described by one of the participants

“I see some gaps on services we offer to our patients. For instance, if a palliative care patient has been admitted, all the charges towards his or her stay has to be squared by the patient himself or herself except the palliative care drugs. They do struggle.”

(Participant 1)

The “uncooperative palliative patient”

For some of the patients admitted, that system looks a bit like a bait, as if they were tricked into the hospital system and abandoned midway, some patients protest this by acting out their frustration thus becoming uncooperative with the hospital staff during the admission. Dealing with uncooperative patients who refuses care presents a challenging scenario for healthcare providers. During my stay in the hospital, an elderly man enrolled in palliative care, required admission to control exacerbating symptoms and he was admitted into the medical ward. Financing is completely different from that in the palliative care clinic, that is just a few steps away. In the ward, he must pay for the

admission and the services, unlike in the palliative care clinic where drugs and consultation are free. While still concerned about what he sees as the exorbitantly high bills, a doctor walked in, reviewed his case along with the presenting symptoms and requested for an invasive investigation – endoscopy, to rule out other possibilities. It was explained to him that he should not eat in order to carry out the procedure at a certain time. Considering the financial implication of investigation, he decided to boycott the instruction by deliberately eating so as not to do the test. The investigation was postponed to the next day, still he repeated the same thing the next day. His uncooperative demeanour clearly angered the healthcare providers, eventually he spoke up, that he was not interested doing any test without providing any reason. Along the line, required supplemental oxygen therapy, but the man was still concerned about the financial implication of any intervention, and apparently he did not understand the consequences, or rather, he understood, but was prepared for the worst since his entire life fortune and money raised by his family present with him will not be sufficient to foot the current hospital bills, let alone endoscopy and oxygen therapy. It was about this time I learnt about *“the uncooperative and difficult palliative patient”* who was only concerned about being discharged home against medical advice.

Initially, he was not so passionate about speaking with me, perhaps imagining I am just there to coerce or persuade him to carry out the investigations. In fact, he was just lying on the floor just outside the ward with some relative of patients. Was he just taking fresh air outside in the company of others, or was he putting up the act to appear that he is fine and fit for discharge? or was he reasoning that he could cut some of the bill by not staying on the hospital bed? Whatever his intentions, but he later revealed that he was putting up the uncooperative act, not because he wasn't interested in his wellbeing, nor because he just wanted to prove difficult, but because those in the medical ward do not seem to understand his financial limitations. Thus, the patient was taking the apparently most rational decision to the best of his knowledge, within the available resources.

“I have seen patients crying on the day of discharge”

The example of patient above illustrates the difficult situation some patients find themselves during and after admission, as a result the day of discharge is a nightmare and psychological trauma for many. Commenting on this a participant gave another example of a patient who had a bill of 96,000 Malawian Kwacha and all what the family could raise was 12,000 Kwacha.

“...the hospital said you (the patient) will not go unless you square the bill...Palliative care said ‘we do not go beyond this. Our limits are to pay services for patients on the days of reviews. So, we do not pay such bills. The bill is so huge, they came back to us saying your patient is failing to pay the bills... After some time, at the very end it was palliative care paying for the patient, yet we do not have specific budget allocated such... and that can also affect the life span of the (palliative care) project, I have seen patients crying on the day of discharge” Participant 1

The tradition of not presenting to the hospital, or ascribing illness to spiritual attack is common. Consequently, religious leaders have exploited this belief, claiming to be able to heal patients without presenting to the hospital. Nowadays, many are now favouring the use of hospitals rather than trusting implicitly the traditional healers or religious leaders. Some of the patients, however, do combine the two. The department takes a mild approach to the latter provided the herbs or method of treatment they receive at such centres does not pose any danger to the wellbeing of the patients. Nonetheless, the traditional healers and religious leaders still constitute a significant barrier to access to palliative care services.

Training – “in school we don’t learn much about morphine”

Majority of palliative care providers at Nkhoma had some form of training. Even though many started with little or no knowledge and experience in palliative care. Some of the those interviewed claimed that the school curriculum was deficient in providing the required basic training on palliative care. One of the participants said “... in school we don’t learn much about

morphine.” Participant 5. They all acknowledged that the training they received as a member of the team has been very relevant and helpful in fulfilling their duties and some believed having training session at regular intervals would prove useful not only for newer ones in the team but also for older team members. Some who travelled to Bergen, for exchange training described their experience saying:

“...the mission was like an exchange visit. It was like we went there and learn how ... they deal with those conditions, it was very interesting, but also we learnt a lot..., it was very important because some conditions which we have here, they also have there.”

Participant 3

In addition, the Nkhoma hospital palliative care through the collaborating partners in Norway have already trained a good number of nurses and clinical officers in managing palliative care patients in the village, in the community, in the health centres.

The chaplains see patients in the hospital, and also join the team during home visits. However, it was noted that there is no special training in palliative care for the chaplains.

“In Malawi there is no pure training which is for chaplain about palliative care. Most of the people who have an access of going under training are medical team but not specifically for chaplains that can go for a training. ... they introduce the PACAM manual and in that manual, there is a topic about chaplains or spiritual leader religious leader.” Participant 2

On the other hand, some noted that Nkhoma hospital will soon have the most trained palliative care personnel in the whole of Malawi. In addition to the training provided to health care workers at the health centres, community volunteers and other members of the community, some already working in the team will soon graduate with a bachelor’s degree in palliative care.

“So far on the part of the training, Nkhoma hospital is the only hospital in Malawi which at the end of this year or at the end of next year will have four, eeh, four trained people with bachelor’s degree in palliative care. There is no other hospital in Malawi which has got such. It will be only Nkhoma hospital having four people with bachelor’s degree.”

Participant 4

Is false hope to patients the answer?

Traditional healers and witch doctors are losing patients because of the paradigm shift to seeking care in the hospitals, this would also mean reduced income for them. Participant 6 told me *“in the hospital you would say the patient have this condition ... but then the traditional healer would say no, you have been bewitched by somebody, so, you should not take what the hospital has to say but believe this it’s your uncle who has done that.”* Therefore, efforts have been made to train them and cooperate with them, which is yielding positive results. Even though some of the patients admitted to having visited the traditional healers in the past, most denied any interaction with them presently and claims not to have any plans patronizing them in the future. This, however, might be said out of fear of the consequences or disapproval that might result by admitting that. Surprisingly though, I learnt of a nurse in the hospital who also combined the role of a traditional healer. She was not associated with the palliative team, as a result, could not have been included in the research directly.

“In African tradition when the hospital told you ‘this is incurable disease’, then you ought to consult the traditional healers and the oracles, about what the problem is, ...patients normally do that, they go to the traditional healers. So, sometimes traditional healers because of wanting money cheat them, they don’t tell them the truth. And they bring false hope to them. So, we saw a need on that, and we decided to train more than fifty traditional healers within the catchment area ... about the palliative care”

In this section, I have described my findings based on data collected from my observations, patients case files, interview with providers and patients, in addition to my experiences within the hospital and during home visits. Understanding the life of pain and suffering of patients is fundamental to meeting their needs. The organization of the team, its models of palliative care, and the organization of services provided to meet the needs of patients have been reported.

Discussion

In this section I will discuss two findings influencing the palliative care at Nkhoma in line with other evidences available in the literatures. These pertain to patients' experiences and access barriers due to financial constraints, drug policies, drug availability and training. The first subheading will address patients' experiences and most pressing needs in palliative care in the region drawing upon findings documented in the first section, while the next subheading based primarily on the last section in the findings chapter, focuses on ways in which drug policies affect access and utilization of available services, comparing this to other neighbouring countries that have made greater progress in palliative care. A reflexive discussion of the methodology will follow leading to discussions of the trustworthiness and applicability of these findings. But before we go into those discussions, it is vital to provide a brief recap of the objectives of the study.

The main aim of the research was to investigate the strengths and limitations associated with provision of palliative care as experienced by healthcare personnel and patients in Nkhoma Malawi and to describe the provision of palliative care and health worker practices at Nkhoma hospital and identify challenges associated with the use of the opioid medication. Overall, the purpose of the study is to contribute to the improvement of palliative care in the low resource setting of rural Malawi, by strengthening the evidence-base needed for health policy, its implementation and development of clinical practice in palliative medicine.

Figure 5 above (in the findings section) describes the main gaps and barriers identified with Nkhoma palliative care services.

Understanding the pain and suffering of patients

Understanding the life of pain and suffering of patients is fundamental to meeting their needs. The organization of the team, its models of palliative care, and the scope of services provided to meet the needs of patients has been examined and reported. This findings and recommendations are intended to guide quality improvement efforts by decision-makers. It may be beneficial to review aspects that impact directly on the palliative care services, such as access barriers. Recommendations to address social issues and matters relating to drug policy, training, and research to generate evidence on patients' outcomes and effectiveness of care delivered, will ultimately lead to reduction in patients' pain and suffering.

In the low income setting of rural Malawi, unmet socioeconomic needs were frequently reported by patients. These include need for employment, food, clothing, shelter as well as other hygiene necessities such as soap and other basic supplies. These findings are similar to the findings of three rapid evaluation field studies in Palliative care conducted in rural Uganda, Kenya and Malawi (Grant et al., 2011) . Another study conducted in Neno district of Malawi reported similar needs and described how poverty has exacerbated the physical and psychological pressure associated with their illnesses. Similar findings have been described elsewhere in parts of sub-Saharan Africa (Selman, Simms, et al., 2013). The bottom line is that programs addressing the impact of poverty in chronically ill people should be put in place. An example of such is the psychosocial support program at hospice Africa Uganda, to cover patients transport to and from the hospital and other necessities such as food and clothing. The "Comfort fund" goes a long way in reducing anxiety and psychosocial pressure (Jagwe & Merriman, 2007).

The findings show that while some patients are spiritually content, others are groaning spirituality. Guilt, and questions about after life remains unsettled for in the mind of some. Providing culturally relevant care in Malawi involves taking into consideration the spiritual needs of patients. The importance of spirituality in palliative care is reflected the global policy guidance to include the care in palliative services. Spirituality can be hardly objectively measured, however 'peace' and another criterion '*life worthwhile*' are similar but distinct palliative care criteria that

have been used in measuring spiritual well-being in patients (Selman, Speck, et al., 2013). Differences in religious beliefs may present a challenge to the team, when patients religious beliefs do not belong to the majority group or are controversial. For instance, providing spiritual care to patients with traditional African religious beliefs was a challenge to palliative care providers at hospice Africa Uganda. Providers are less comfortable providing care especially when patients hold traditional beliefs in witchcraft and associates illness with cursing (Kale, 2011).

Geographic factors such as long distance and terrain to hospitals limit access to care. In some cases, patients are too weak to embark on such long walk to health facilities. Often the travel is associated with physical, emotional and financial burden to patients (Grant et al., 2011). At Nkhoma hospital and other major (district) hospitals, it was reported that an effective and functional morphine supply chain exists. However, the unavailability in the health centres that are closer to the patient, mean that many patients must travel to secondary or tertiary level hospitals to assess palliative care. Several setbacks are associated with the journey and travel to hospital, including long distances, lack of means of transportation in some settings, difficult terrain and cost of transportation is too high for some.

Morphine is listed among essential drugs in the Essential Health Package Medicines and Supplies list (Ministry of Health of Malawi., 2004). Studies have found the over-restriction of morphine is actually counter-productive and fear of misuse have been described as 'unwarranted' (Knaul et al., 2018). In fact, a study revealed that the cost to cover morphine need in all the low-income countries is less than \$70 million compared with \$100 billion spent annually by governments around the world in enforcing prohibition of drug use (Knaul et al., 2018).

Many patients enrolled in the palliative care program at Nkhoma Malawi are diagnosed with HIV/AIDS, most of whom are young adult. These reflect the overall demographics of the HIV epidemic, with high prevalence in Malawi, according to UNAIDS global report. This is similar to findings from rural districts of Malawi, with most being young adults infected with HIV (Herce et al., 2014). Many are also receiving chemotherapy on account of Kaposi sarcoma – which is a type

of cancer associated with patches of abnormal tissue growth beneath the skin, in the lining of the mouth, nose, throat and in lymph nodes, or in other organs in the body.

It is important to mention that Liver cirrhosis was the commonest single disease present in patients enrolled in palliative care at Nkhoma. The high prevalence of Liver Cirrhosis and hepatitis infection in the population has not received much attention. Viral hepatitis has been an important public health problem in sub-Saharan Africa, and it is associated with rising mortality from cirrhosis and hepatocellular carcinoma. There are extremely limited screening programs and treatment options, and that is why it is described as a “neglected tropical disease” a recent systematic review (Stockdale et al., 2018). In an informal chat, a staff in the hospital opined that the high prevalence of viral hepatitis may be due to low vaccination coverage. At any rate, generating new evidence on the prevalence and associated factors as well as synthesis of the existing evidence on its epidemiology is necessary to inform policies and actions that will address this neglected public health issue.

Bridging palliative care access gaps through drug policy, training and research

Despite the efforts of the World Health Organization and other regulating bodies to increase coverage of palliative care services in Africa, coverage remains terribly limited. This discussion will follow the WHO four pillars strategy that includes policy, education, drug availability, and implementation (Harding et al., 2013). The following is a discussion of how these pillars can lead to improved coverage and quality of palliative care services for patients with advanced cancer and other life-limiting illnesses at Nkhoma.

The first pillar is policy, it affirms that palliative care growth is policy dependent. In a low income setting like Nkhoma, drug policy is especially important. Health policy must take into consideration the scarcity of resources and the needs of dying patients and their families. An often-cited possible reason for the restrictive policy on opioid is that the community health centres do not have doctors. An examination of the drug policy at Uganda shows that the

country attained advanced integration only after an amendment of the 1993 National Drug Policy and Authority Statue. This amendment took place on April 23, 2004 and it allowed not only medical practitioners and dentist to prescribe Morphine, but also palliative care nurses and clinical officers. Consequently, palliative care became potentially available for the 86% of Ugandan population living in rural areas (Jagwe & Merriman, 2007). Traditionally, injectable morphine has been recognized as very effective analgesic, in recent times, however, it has been demonstrated that oral morphine is also highly effective. Consequently, stringent drug regulations and associated fear of addiction especially with injectable morphine have faded away in many countries (D. R. Harding, 2007).

The second pillar is education and communication. Patients with chronic illnesses often need improved communication and additional information about their diagnoses, prognosis, and the implications of their diseases. In Malawi, palliative care is a relatively novel concept, therefore, training is essential to increase sensitization, dispel myths about opioids use, such as the fear of addiction emphasizing that addiction is rare when morphine is used for severe pain (World Health Organization, 2000). Education and trainings provided even to non-healthcare workers that are volunteers in the community has also been shown to be beneficial (Claxton-Oldfield, 2015). It has been advocated that palliative care training should be properly integrated into undergraduate medical and nursing curriculum (Felicia Marie, 2018). In line with this the government of Malawi as well as foreign partners are stepping up the training of healthcare workers and community volunteers to meet not only the physical needs of patients but also the emotional and spiritual needs. This was evident during my stay, as some students came for a short period of internship in palliative care at Nkhoma hospital. However, at the time of data collection, those desiring to have a bachelor's degree program in palliative care would need to travel to universities outside Malawi, such as those in Uganda

The third pillar, drug availability is closely linked with governmental policies on drugs. Substantial challenges face drug availability and distribution for palliative care in sub-Saharan Africa, with data suggesting that at least 88% of cancer deaths with moderate to severe pain are untreated. Although the WHO essential medicines list includes drugs necessary for delivery of palliative care in line with the organisation's pain ladder, research on drug availability has shown that even step

1 analgesics (for example paracetamol) are sometimes unavailable and that supply is unreliable (Harding et al., 2013). While pain medications were available at Nkhoma hospital, which is considered a secondary centre, the availability of simple non-opioid pain killers at the health centres, were beyond the scope of this research. Most of the patients registered with Nkhoma palliative care live far away from the hospital, and although some have health centres within their proximity, current legislation does not permit health centres in Malawi to keep opioids. However, under-prescription has been described as the real concern, and because of the focus on primary care, other countries such as South Africa have declared morphine and codeine essential drugs in primary care settings and a national standard for pain control is also in place (Logie & Harding, 2005).

The fourth pillar, implementation, is exemplified by evidence demonstrating that policies, education, and drug availability alone are not adequate for sustained change in the provision of palliative care services. Thus, a balance between quality of palliative care and coverage is desirable, this will enable policies and services to be implemented not only at central or district hospitals, but throughout the health system reaching the peripheral centres. Validated patient outcome measures and improved use of audit methods designed to optimize allocation of scarce resources may be useful in replicating successful clinical approaches.

In addition, Harding et al. presented evidence for and proposed a fifth pillar of research activity, which will stimulate improvement of care by giving increased attention to the generation of evidence through research, arguing that the other four pillars discussed above is not sufficient to fully integrate the care into the health system, without generation of quality evidence through research (Harding et al., 2013).

Methodological strength and challenges in the palliative care research

A clear exposition of method used is appropriate to judge a qualitative research. As explained in the method section a qualitative study was used involving documentation, interviews, and observations. This is similar to the rapid evaluation methodology (REM), which was designed by the World Health Organization (WHO) for collection of data through field-based interviews along with observations. This has been used in scientific publications, including those about palliative care services in sub-Saharan Africa to guide quality improvement efforts by planners and decision-makers, and provide a basis through which operational problems can be identified for managerial action to be taken (Anker et al., 1993).

Despite scepticism of subjectivity in qualitative research, it is gaining increasing acceptance (Mays & Pope, 2000) as its methodology are constantly undergoing refinement to ensure credibility, transferability and dependability, factors such as preconceptions and reflectivity have also been identified to affect research (Malterud, 2001) (Green & Thorogood, 2018). Several methods of data were used to ensure accuracy, trustworthiness, and comprehensiveness of data, to strengthen its applicability in improving palliative care services at Nkhoma, Malawi. This is in line with quality qualitative research described by Mays and Pope (Mays & Pope, 2000). Data were gathered from the clinic documentations, palliative care provider interviews, observation and participation in task performance. The interview also included, group discussions, patients' interviews, as well as household interviews. The use of two or more sources of data may compensate for weaknesses in one method of data collection, and while it may not be a pure test of validity, it does increase comprehensiveness. This is referred to as triangulation (Mays & Pope, 2000). Having representatives from all the cadres of health workers in the team, as well as diverse patients in the study is considered a way obtaining different perspectives, which may increase its credibility (Graneheim & Lundman, 2004).

I was sensitive to the ways in which my background as a Nigerian and a male medical doctor could have shaped the research process. Since I looked like every other Malawian, my presence during the home visit did not attract undue attention, thus not distracting from the purpose of

the visit and this was very favourable for passive observation. I was also able to learn the basic greetings in Chichewa. Sometime after completing my medical degree - (MD) in eastern Europe, I moved to Africa where I practiced as a doctor for 6years, before embarking on a master's degree in Global health. Therefore, the working environment and the cases seen at Nkhoma hospital, Malawi reflect my previous experiences, as a result, integrating in such environment was no challenge. On the other hand, having an interpreter who was a member of the team compensated for not being able to speak Chichewa.

Although my presence in the department was primarily as a researcher, my status as a medical doctor in a unit with no doctor presented an initial role definition challenge for some days until a reasonable balance was achieved between participation in patients consultation and clinical reviews and my role as a researcher. These roles can be justifiably argued in either directions. On the other hand, being a doctor was a source of confidence and trust, as it made participants especially patients and guardian more comfortable to express themselves.

Bracketing is the term used when researchers keep in abeyance preconceptions, biases and previous knowledge and experiences to mitigate their potential effects on the research, and can also protect the researcher during an emotional challenging research (Tufford & Newman, 2012). As a researcher, I needed to bracket off my clinical beliefs and professional experience, so as not to influence the responses given, which was challenging at times. For instance, I was forced to correct an erroneous notion a husband had concerning their sickle-cell son, when I realized the lack of basic medical knowledge was causing a major rift in the family, resulting in breakup. This is because the husband strongly believed the wife was sorely responsible for the sickle cell disease in their son. It was necessary to correct his views, in my opinion despite 'bracketing' (Britten, 1995). Reflecting on my preconceptions and prestudy beliefs (Malterud, 2001), I was aware of general shortage of Morphine and its scarcity in Africa, however, there was adequate supply of the drug and apparently functional opioid supply chain in the hospital at the time of data collection, even though other essential drug (Vincristine) ran out of stock in the country. On the contrary, Morphine was not accessible to patients at the health centres in the communities.

Some of the interviews were done in the presence of a family member or guardian, at the request of the patients, with comments coming from the patients and the family member or guardian. Having the guardian present might interfere negatively, hindering the patient from expressing his or her feelings and experiences. However, in most cases it proved beneficial as a form of error reduction mechanism, since the message being relayed was being confirmed or counteracted by the other person present, thus a form of “member checking,” or respondent validation. In the book, *Techniques of validation in qualitative research: a critical commentary*, the writer argued that the typical respondent validation has its limitations too, implying that the account produced by the researcher may vary from that of individual participant. This is because the researcher has accounts obtained from others and the result is meant for a wider audience (Bloor, 1997).

At the beginning of the research a semi structured open ended interview guides was developed, the flexibility of an interview guide in the field often lead to an improved quality qualitative interview (Dicicco-Bloom & Crabtree, 2006). A less rigid structure favors in-depth interviews, unlike the highly structured survey interviews and questionnaires used in epidemiology (Britten, 1995) Most of the interviews with care receivers were conducted within the health facilities soon after contact with the health services and being attended to in the palliative care clinic, such clinic exit interviews could have affected the responses obtained, as the encounter is still fresh (Britten, 1995) (Anker et al., 1993). These interviews were also an opportunity to find out the clients’ experience during that clinic visit, and then earlier encounters. An exploration of satisfaction or dissatisfaction with the services rendered was probed into as well as other challenges encountered in seeking healthcare. Assured of the confidentiality, patients and their relatives readily expressed themselves which also increases the trustworthiness of the findings.

Methodological challenges associated with palliative care research are well documented (Johnston & Abraham, 1995). Difficulty exists in defining and measuring what constitute appropriate outcomes in palliative care. This is because palliative care encompasses not only physical symptoms, which can be operationalized but also factors like communication, social welfare, spiritual health and quality of life and death. These outcomes are also very subjective and patient-defined, depending on the individual’s perspective and the interpretation may vary

with cultural orientation. A longitudinal study would be required to track changes over time, thus objectively measuring the effectiveness of palliative care services provided was beyond the scope of this qualitative study.

There were major weaknesses in the home-based interviews, and many were excluded from the study. Some of the patients were too weak to fully participate and since the visit was with the team, ensuring confidentiality in the presence of other team members was impractical.

Furthermore, the responses from these interviews could be biased towards a positive evaluation of the services, due to the presence of team members and the coordinator during the visits.

During my stay, not many home visits were conducted due to financial constraints and the resultant inability to fuel the ambulance, resulted in me visiting about five patients in their homes. All these patients were excluded from the report because of the poor quality of the interviews due to the aforementioned factors. A 14-year-old boy we met during one of the home visits was also excluded because he was not up to the age of consent for this study. Nonetheless, observations from the home visits were valuable in the findings write up and recommendations.

Conclusion

The main aim of the research is to investigate the strengths and limitations associated with provision of palliative care as experienced by both the palliative care providers, and care recipients in the palliative care program at Nkhoma Hospital, Malawi.

This study has demonstrated that while palliative care services are available at Nkhoma hospital, access gaps exist. Optimum palliative care in Nkhoma region of rural Malawi, depends on meeting socioeconomic needs of patients, as well as making policies that ensure opioid pain killers are available to patients when they need it, and within their close proximity. Findings from this study may be context specific, which is true of most qualitative research. Nonetheless, the clearly explicated methods of data collection and analysis, as well as efforts put in place to ensure its credibility, therefore, makes it safe to assume that the findings would likewise reflect the experiences of palliative care providers and care recipients in similar areas across Malawi. However, as policies and income level of patients keep changing, some of the findings may change and need to be interpreted considering current situation and adapted accordingly.

The findings reveal the multiple and interconnected challenges associated with living with chronic life-limiting illnesses and poverty, and how psychosocial and spiritual distress can contribute significantly to the total pain. In line with the palliative care holistic approach, serious attention should be given to psychological, socioeconomic, and spiritual distress, as well as improved access to opioid pain-relief medications at centres closer to patients.

Recommendations

These recommendations are based on findings from the review of Nkhoma palliative clinic documentations, health staff interviews, observations, group discussions, patient's clinic-exit interviews and household interviews as well as checking of facilities.

- Existing medicine regulation appear restrictive for a low-income setting. Relevant health authority in Malawi can be contacted to discuss the possibility of easing legislation regarding opioid distribution. A pilot risk-benefit assessment of easing legislation concerning opioid distribution might be conducted. Having the drugs closer to the patients will reduce the cost of transportation for both the providers and the recipients, which consume a huge proportion of home-based care budget.
- Policy makers, foreign partner organisations and the palliative care team need more evidence concerning the needs of patients, and the effectiveness of care provided at Nkhoma, despite the positive feedbacks from patients, which is typical in any palliative care services. Measuring the outcomes and effectiveness of care delivered, using the APCA - African Palliative Care Association's palliative outcome scale, might be the subject of subsequent research studies.
- Sponsors should consider starting programs addressing the impact of poverty in patients with life-limiting illnesses. An example of such is the psychosocial support program at hospice Africa Uganda known as the "Comfort fund" that covers patients' basic necessities such as food, clothing, shelter and transportation to the hospital.
- Priority setting in palliative care should be of concern to the sponsors and the providers. Scarce resources and financial constraint make equitable distribution more important among the patients. Audits and costing of components of the services should be carried out, and a cost-benefit analysis might be performed to evaluate aspects of services offered.

- As shown in the findings about 11% of patients enrolled are children, it is therefore important to find support from Children Organizations such as UNICEF. The assistance provided may address physical, emotional, or spiritual aspect of care in the children.
- Integrate palliative care education and training into mandatory undergraduate and more in-depth postgraduate curricula of relevant disciplines, especially those that work with significant numbers of people with life-limiting conditions. Continuing professional education should include palliative care content.
- The front page of the patient file could be redesigned or labelled in a way to make it immediately evident what form of treatment the patient is receiving - curative and/or palliative care, and reasons for not exploring curative treatment (pharmacological or nonpharmacological options) should be clearly document if that is the case. This will ensure curative options have been explored for all patients.
- Significant positive results have been achieved through the trainings provided by Norwegian partners. For continuous development, short refresher trainings might be beneficial for the hospital-based team as well as non-hospital-based team members.
- Efforts should be made by the team, perhaps in collaboration with donors, to be financially independent to ensure sustainability of the program. The hospital for instance generates funds through donated buildings rented out to visitors. This can also be done by palliative care, or buildings donated to palliate care, if any, reclaimed and funds generated from it used to take care of the social needs of patients.
- Community volunteers are important part of the team. A little compensation giving to them for the costs incurred, for instance transportation to the hospital, or other incentives occasionally, might go a long way in keeping them motivated.

Appendices

1. Information Sheet and Consent Form (English)

INFORMATION SHEET

Research Topic: “Palliative Care Service Provision in Nkhoma, Rural Malawi - Exploring Experiences of Healthcare Providers and Care Recipients”

Background and purpose

This research is part of a master study in Global Health performed at the University of Bergen in Norway. The study is attached to collaborations between institutions in Norway and Malawi on provision of palliative care in Nkhoma District. It has a particular focus on access to medicines. The aim of the study is to improve our knowledge of what works and what does not work in the programme seen from health workers and patient/care givers point of view. The overall goal is to provide knowledge that can be used to improve the programme.

What does the study entail?

For this study you will be asked to participate in an interview. If you consent, we will record the interview. The interview will be in English and/or your local language. It will take from 45 to 60 min. All information will be kept strictly confidential and protected from unauthorized access.

What will happen to the information about you?

The data that are registered about you will only be used in accordance with the purpose of the study as described above. All the data will be processed without name or other directly recognisable type of information.

Voluntary participation

Participation in the study is voluntary. You can withdraw your consent to participate in the study at any time and without stating any particular reason. If you wish to participate, please sign the declaration of consent. If you later on wish to withdraw your consent or have questions concerning the study, please contact Adeosun Olawale on +4798861454 or +2349031780641 or via email: Olawale.Adeosun@student.uib.no

CONSENT FORM

Consent for participation in the study

I have read and understood / been read and understood the information about this study and what it entails to me as a study participant. I have had the opportunity to ask questions about the study and any questions I had have been answered to my satisfaction.

I consent voluntarily to participate in the study.

(Signed by the project participant, date)

I confirm that I have given information about the study.

(Signed, role in the study, date)

2. Information sheet and Consent Form (Chichewa)

INFORMATION SHEET

Mutu Wosanthula: "Ntchito Yothandizira Pakati pa dera lozungulira chipatala cha Nkhoma ku Malawi - Kufufuza Zochitika za Omwe Amagwira Ntchito Zaumoyo ndi Othandizira"

Zomwe zikuchitika ndi cholinga

Kafukufukuyu ndi gawo la maphunziro a Global Health ku yunivesite ya Bergen ku Norway. Phunziroli likuphatikizidwa ku mgwirizano pakati pa mabungwe ku Norway ndi Malawi chifukwa chokhala ndi chisamaliro chapadera cha odwala matenda amgonamgona mu dera lozungulira chipatala cha Nkhoma. Kafukufukuyu ali ndi cholinga makamaka pa mwayi wa mankhwala ndi zomwe odwala komanso a zaumoyo amakumana nazo. Cholinga cha phunziroli ndikutithandiza kudziwa bwino zomwe zimagwira ntchito komanso zomwe sizigwira ntchito mupulogalamuyi mowonetsedwa kuchokera kwa ogwira ntchito zaumoyo, odwala komanso osamalira odwala. Cholinga chachikulu ndicho kupereka chithuzithuzi cha zomwe zingagwiritsidwe ntchito kupititsa patsogolo pulogalamuyi.

Kodi phunziroli limaphatikizapo chiyani?

Phunziro ili mudzafunsidwa kutenga nawo mbali pa zokambirana. Ngati mutavomereza, tidzakambirana nkhanayi. Kuyankhulana kudzakhala mu Chingerezi ndi kapena chinenero chanu. Zidzatenga mphindi zosachepera 45 kapena 60. Uthenga onse udzasungidwa mwachinsinsi ndi mosamalitsa.

Nchiyani chiti chidzachitike pazomwe mukudziwa zokhudza inu?

Uthenga womwe udzalembedwe kukhudza za inu udzagwiritsidwa ntchito molingana ndi cholinga cha kafukufukuyu monga tafotokozera pamwambapa. Uthenga wonse udzasinthidwa popanda dzina kapena mtundu wina wodziwika bwino.

Kudzipereka mwachangu

Kutenga mbali pakafukufukuyi ndi mwaufulu. Mukhoza kuchotsa chilolezo chanu kuti muchite nawo kafukufuku panthawi iliyonse komanso popanda chifukwa china chilichonse. Ngati mukufuna kufotokozera, chonde lembani chilolezo chovomerezeka. Ngati mukufuna kubweza chilolezo chanu kapena ngati muli ndi mafunso okhudza phunzirolo, chonde funsani Dr Adeosun Olawale pa +4798861454 kapena +265991682355 kapena kudzera pa imelo Olawale.Adeosun@student.uib.no

KALATA YACHILOLEZO

Kutenga nawo mbali pa pafukufukuyi

Ndawewerenga ndikumvetsetsa / ndawerenga ndikumvetsa bwino za kafukufukuyi komanso zomwe zafotokozedwa za ine monga otenga mbali. Ndinapatsidwa mwayi wofunsa mafunso okhudzana pakafukufukuyi ndipo mafunso onse omwe ndinali nawo ndayankhidwa mokhutira. Ndikuvomereza mwa kufuna kwanga kuti ndichite nawo kafukufukuyi.

(Zasainidwa ndi wotenga mbali mu polojekiti, tsiku)

Ndikutsimikizira kuti ndapereka zambiri zokhudza kafukufukuyi.

(Sayini, gawo mu kafukufukuyi, tsiku)

3. Interview Guide

Welcome to the interview and thank you for agreeing to be a part of this study.

PALLIATIVE CARE TEAM & SERVICES

1. What is your understanding about the need for palliative care in this region?
 - a. What are the commonest conditions in this region that requires palliative care?
 - b. What challenges do patients with chronic diseases face?
 - c. How are the needs of patients' caregiver or relatives cared for?
2. How do the patients perceive the care received in the hospital (inpatients and outpatient basis)?
3. What challenges and barriers do you encounter in provision of care?
4. Can you relate your experiences over the years in provision of palliative care?

Treatment and Morphine

5. What medications are available for use in providing relieve to patients' physical needs?
6. How easy or challenging is it to get the required medications (drug availability)?
7. What are your experiences and perceptions about allowing patients to have the drugs at home
8. What are your reservation about the use of morphine?

Support – Physical, Psychological, Social, Spiritual

9. What are your thoughts about the capacity of the team to handle the challenges associated with palliative care?

Future

10. What can be done to improve palliative care services in this region?
11. Do you have anything else you would like to add?

CARE RECEIVERS

Challenges, Experiences & quality of life

1. Can you please tell me about yourself and your condition?
 - a. What are the major challenges that you face?
2. If you have symptoms, (e.g. pain or discomfort, constipation, shortness of breath, nausea or feeling sick, lack of appetite, tiredness, dry mouth) what do you do / where do you seek help and what are your reasons for that choice? (traditional healers, hospital, pharmacy)
3. What is your experience with pain relief and access to medicines?
4. How do you experience the quality of the care provided?
 - a. Have there been significant improvements in your symptoms since you started treatment?
 - b. Are you satisfied with the treatment here?
5. What do you think may improve the care?
6. Do you have anything else you would like to add?

Thank you very much participating in this study.

4. Participatory observation Guide

The researcher would be involved in a general observation within the outpatient department and during home visits. Practices, interaction, care challenges and the manner in which the palliative care is carried out in the hospital would be observed. This will help to explore both the strength and limitations. A daily observatory diary would be used to note these findings and to ensure reproducibility and accuracy.

Specifically, the researcher will pay attention to the following:

In the outpatient department:

- Availability of drugs
- Infrastructure
- Staffing
- Interaction between health care personnel and patients
- Waiting times

During home visits:

- Distance to medication and care centre
- Living conditions
- The wellbeing of the patients
- The interaction between the home-based care team and the patients/care givers in the home

Noteworthy findings would be included in the thesis and/ or publication at the end of the study.

5. Letter from Haraldsplass hospital



COMREC
College of Medicine
Research Ethics Committee
University of Malawi

Bergen 17.04.19

Haraldsplass
Diakonale Sykehus
Tlf: 55 97 85 00
hds@haraldsplass.no
Besøksadresse:
Ulriksdal 8 5009 Bergen
Postadresse:
Haraldsplass
Diakonale Sykehus
Postboks 6165 5892 Bergen
www.haraldsplass.no

LETTER FROM HARALDSPASS DEACONESS HOSPITAL

Haraldsplass Deaconess Hospital, Norway have had a collaboration with Nkhoma Mission Hospital, Malawi since 2010. The first five years with exchange of health care personnel with focus on acute and critically ill patients and competence building. During this period, we saw the need for strengthening the competence on palliative care. In 2016 a project was established together with Hospice Lovisenberg, Norway and Nkhoma Mission Hospital. The focus is competence building and to make the distance between patients and hospital smaller. We also wanted to get in contact with master students from Centre for International Health (CHI), University of Bergen to do research on the progress of palliative care and to document the strengths and weakness of the implementation.

The need for palliative care in low-income countries is increasing due to increased life expectancy and CHI aims to contribute to an evidence base that can be used to improve healthcare.

Adeosun Olawale, a medical doctor and a master student at CHI will be looking into palliative care at primary level, both in the hospital and in home base care in Nkhoma. His supervisors from CHI who are responsible for the research will assist him. The findings from the study will contribute to knowledge about palliative care in rural district of Malawi.

Thank you for your cooperation.

Sincerely,
Aina Therese Drengenes, Nurse
Coordinator of palliative care project
Haraldsplass Deaconess Hospital, Norway

6. Letter from Nkhoma Hospital



Nkhoma CCAP Hospital

All correspondence to be addressed to The Principal Hospital Administrator



19 April 2019

College of Medicine Research and Ethics Committee (COMREC)
College of Medicine
P/Bag 360
Chichiri
Blantyre 3
Malawi

Re: Provision and Experience of Palliative Care in Nkhoma District

Dear Sir,

The above research project has been proposed by the Haraldsplass Deaconess Hospital and Center for International Health in partnership with Nkhoma CCAP Hospital.

The related project fieldwork will be carried out at Nkhoma CCAP Hospital by the postgraduate student Olawale Adeosun, under the supervision of Dr Catherine Hodge at Nkhoma Hospital, Malawi. This is proposed to take place in and around July through September 2019.

The management team of Nkhoma CCAP hospital fully supports it recognising that the outcome of this research proposal will benefit the patients and community of Nkhoma CCAP Hospital.

We hope that the attached project outline will meet the standards set by COMREC and that the committee will look favourably upon this proposal and provide its approval.

Yours Sincerely,

Catherine Hodge, M.D.
Deputy of Medical Education
Nkhoma Mission Hospital
+265 885422106

P.O. Box 48, Nkhoma, Malawi
Private Bag 206, Lilongwe, Malawi
☎: 265-9-9971069
🌐: www.nkhomahospital.org.mw

Bank details:
National Bank Malawi
Lilongwe Branch
PO Box 123, Lilongwe
Malawi
Swift code NBM AM WMW

Nkhoma Hospital Euro Account, number: 267706; Nkhoma Hospital Dollar Account, number: 256773;
Nkhoma Hospital Pound Account, number: 365033; Nkhoma Medical Account number: 1609912

Serving with Love and Care

7. Ethical approval Malawi

Telephone: + 265 789 403
Facsimile: + 265 789 431

All Communications should be addressed to:

The Secretary for Health and Population



In reply please quote No.

MINISTRY OF HEALTH AND POPULATION

P.O. BOX 30377
LILONGWE 3
MALAWI

5th July, 2019

Alexander Asiedupe
University of Bergen

Dear Sir/Madam,

Re: Protocol # 1985/2348: Palliative Care Services in Nkhoma District of Rural Malawi - Exploring Experiences of Palliative Care Providers and Care Recipients

Thank you for the above titled proposal that you submitted to the National Health Sciences Research Committee (NHSRC) for review. Please be advised that the NHSRC has reviewed and approved your application to conduct the above titled study.

- APPROVAL NUMBER : 2348
- The above details should be used on all correspondences, consent forms and documents as appropriate.
- APPROVAL DATE : 05/07/2019
- EXPIRATION DATE :
This approval expires on 04/07/2020. After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the NHSRC Secretariat should be submitted one month before the expiration date for continuing review.
- SERIOUS ADVERSE EVENT REPORTING: All serious problems having to do with subject safety must be reported to the NHSRC within 30 working days using standard forms obtainable from the NHSRC Secretariat.
- MODIFICATIONS: Prior NHSRC approval using forms obtainable from the NHSRC Secretariat is required before implementing any changes in the protocol (including changes in the consent documents). You may not use any other consent documents besides those approved by the NHSRC.
- TERMINATION OF STUDY: On termination of a study, a report has to be submitted to the NHSRC using standard forms obtainable from the NHSRC Secretariat.
- QUESTIONS: Please contact the NHSRC via phone number +265 999 397 913 or by email on malawi@nhsrc.gov.mw
- ETHICS: Please be reminded to send us copies of your final research results for our records (Health Research Database).

Kind regards from the NHSRC Secretariat.

For CHAIRPERSON, NATIONAL HEALTH SCIENCES RESEARCH COMMITTEE
Promoting Ethical Conduct of Research!



Executive Committee: *Dr. B. Chitima (Chairperson), Dr. B. Njirira (Vice-Chairperson)*
Registered with the USA Office for Human Research Protections (OHRP) as an International IRB/ERB
Number IRB00003905 FWA00005976

8. Ethical approval Norway



REGIONALE RÅDTELER FOR MEDISKE OG HELSEINGLIG FORSKNINGSETIKK

Region: REK nord	Saksbehandler: Veronica Sørensen	Telefon: 77620758	Vår dato: 14.06.2019	Vår referanse: 2019/609/REK nord
			Deres dato:	Deres referanse:

Vår referanse må oppgis ved alle henvendelser

Karen Marie Moland
University of Bergen

2019/609 "Palliative care services in Nkhoma District of rural Malawi: Exploring experiences of providers and care recipients"

Haralds plass Hospital has in collaboration with the Ministry of Health, Malawi, started a project to develop palliative care competence and services in Nkhoma District in rural Malawi. The project was supported by Fredskorpset in the initial phase and is now supported by several actors Side 3 av 11 including Lovisenberg Hospital. Haralds plass Hospital contacted Centre for International Health to recruit master students to do research on the project components. The project that we now submit to REK for ethical clearance is developed in close collaboration with Haralds plass Hospital and in agreement with their partner in Malawi, located at Nkhoma District Hospital.

We can confirm that the project 2019/609 "Palliative care services in Nkhoma District of rural Malawi: Exploring experiences of providers and care recipients", is approved by the regulatory committee for research and ethics (REC north).

Best regards

Veronica Sørensen
senioradvicer

Søkesadressen:
MH-bygget UJT Norges arktiske
universitet 9037 Tromsø

Telefon: 77946140
E-post: rek-nord@ep.uj.no
Web: <http://www.forskningsetikk.no/>

All post og e-post skal innlegges i
saksbehandlingens, bes adressert til REK
nord og ikke til enkelte personer

Kindly address all mail and e-mails to
the Regional Ethics Committee, REK
nord, not to individual staff

9. Ethical approval Norway (Norwegian)



Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK nord			25.04.2019	2019/609/REK nord
			Deres dato:	Deres referanse:
			19.03.2019	

Vår referanse må oppgis ved alle henvendelser

Karen Marie Moland
Senter for internasjonal helse

2019/609 Palliativ omsorg i Malawi

Forskningsansvarlig institusjon: University of Bergen
Prosjektleder: Karen Marie Moland

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK nord) i møtet 11.04.2019. Vurderingen er gjort med hjemmel i helseforskningsloven (hforskn) § 10.

Prosjektleders prosjekttale

Palliative care is rapidly developing in Africa, but it is still in its infancy and coverage is extremely limited. Studies have found that only 0,03% of available opioids pain killers is distributed to low Income countries (LIC). One initiative to address the lack of capacity in palliative care is a collaboration between Haraldsplass Hospital and Nkhoma Hospital in rural Malawi. The project aims to develop services to end of life patients and establish a model centre for palliative care. In partnership with the palliative care team established through this project, we aim to explore strengths and limitations associated with the provision of palliative care as experienced by health care personnel and patients. We will use a qualitative research approach to gain insight into end of life care at primary healthcare level and patient follow up, and to describe gaps in the provision of care. In particular we will identify challenges related to access to medicine and especially morphine.

Om prosjektet

I denne studien skal man følge medisinsk personell i Malawi ved Nkhoma sykehus som gir palliativ omsorg. Disse skal intervjues om sin forståelse av behovet for palliativ omsorg, og hvilke forhold, utfordringer og barrierer som eksisterer rundt det å skulle gi palliativ omsorg.

Det skal også intervjues 10-15 pasienter og deres familier om behandlingen, herunder om tilgang på medisin, oppfølging og hvor fornøyde de er med tilbudet som blir gitt.

Formålet er å gi en kvalitativ beskrivelse av hvordan palliativ omsorg utføres ved Nkhoma sykehus og tilgang på smertedempende midler.

Mindreårige

I søknaden står det oppført at «Children below 18 years» er et eksklusjonskriterie, mens det i protokollen på s. 9 står at "Willing participants will individually give consent, preferably written (see Appendix 2), except in the case of a minor (where the parent(s) and/or a guardian will take the responsibility."

Etter helseforskningsloven er myndighetsalderen for deltagelse i helseforskningsprosjekter i Norge 16 år.

Besøksadresse:
MIS-bygget UIT Norges arktiske
universitet 9037 Tromsø

Telefon: 77846140
E-post: rek-nord@isp.uit.no
Web: <http://helseforsknings.etikkom.no/>

All post og e-post som inngår i
saksbehandlingen, bør adressert til REK
nord og ikke til enkelte personer

Kindly address all mail and e-mails to
the Regional Ethics Committee, REK
nord, not to individual staff

References

- Anker, M., Guidotti, R. J., Orzeszyna, S., Sapirie, S. A., & Thuriaux, M. C. (1993). Rapid evaluation methods (REM) of health services performance: Methodological observations. *Bulletin of the World Health Organization*, 71(1), 15–21.
- Bates, J., Gwyther, L., & Dinat, N. (2008). Morphine: Friend or foe? *Malawi Medical Journal : The Journal of Medical Association of Malawi*, 20(4), 112–114.
- Bloor, M. (1997). Techniques of Validation in Qualitative Research: A Critical Commentary. In G. Miller & R. Dingwall, *Context and Method in Qualitative Research* (pp. 38–50). SAGE Publications Ltd. <https://doi.org/10.4135/9781849208758.n3>
- Brennan, F. (2007). Palliative care as an international human right. *Journal of Pain and Symptom Management*, 33(5), 494–499. <https://doi.org/10.1016/j.jpainsymman.2007.02.022>
- Britten, N. (1995). Qualitative Research: Qualitative interviews in medical research. *BMJ*, 311(6999), 251–253. <https://doi.org/10.1136/bmj.311.6999.251>
- Brumley, R., Enguidanos, S., Jamison, P., Seitz, R., Morgenstern, N., Saito, S., Mcllwane, J., Hillary, K., & Gonzalez, J. (2007). Increased Satisfaction with Care and Lower Costs: Results of a Randomized Trial of In-Home Palliative Care. *Journal of the American Geriatrics Society*, 55(7), 993–1000. <https://doi.org/10.1111/j.1532-5415.2007.01234.x>
- Casarett, D., Pickard, A., Bailey, F. A., Ritchie, C. S., Furman, C. D., Rosenfeld, K., Shreve, S., & Shea, J. (2008). A nationwide VA palliative care quality measure: The family assessment of treatment at the end of life. *Journal of Palliative Medicine*, 11(1), 68–75. <https://doi.org/10.1089/jpm.2007.0104>
- CDC. (n.d.). *Malawi—Traveler view | Travelers' Health | CDC*. Retrieved June 11, 2020, from <https://wwwnc.cdc.gov/travel/destinations/traveler/none/malawi>
- Clark, D. (2016). *To comfort always: A history of palliative medicine since the nineteenth century*. Oxford. *Oxford University Press*, 2016.
- Claxton-Oldfield, S. (2015). Hospice palliative care volunteers: The benefits for patients, family caregivers, and the volunteers. *Palliative & Supportive Care*, 13(3), 809–813. <https://doi.org/10.1017/S1478951514000674>
- Connor, S. R., Sepulveda Bermedo, M. C., Worldwide Palliative Care Alliance, & World Health Organization. (2014). *Global atlas of palliative care at the end of life*.
- Council of Europe. (2003). *Recommendation 24 of 2003. Adopted by the European Committee of Ministers*.
- Danielsen, B. V., Sand, A. M., Rosland, J. H., & Førlund, O. (2018). Experiences and challenges of home care nurses and general practitioners in home-based palliative care – a qualitative study. *BMC Palliative Care*, 17(1), 95. <https://doi.org/10.1186/s12904-018-0350-0>

- D.E. Meier, & L. Beresford. (2008). Outpatient clinics are a new frontier for palliative care. *Journal of Palliative Medicine*, 823–828.
- D.E. Meier, S.L. Isaacs, & R.G. Hughes (Eds.). (2010). The development, status, and future of palliative care. Palliative care: Transforming the care of serious illness. *Robert Wood Johnson Foundation, Princeton*, 1–76.
- Definition of hospice. *MedlinePlus*. (n.d.). [Text]. National Library of Medicine. Retrieved May 8, 2020, from <https://medlineplus.gov/hospicecare.html>
- Dicicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview. *Medical Education*, 40(4), 314–321. <https://doi.org/10.1111/j.1365-2929.2006.02418.x>
- Dix, O. (2012). *Impact of the APCA African Palliative Outcome Scale (POS) on care and practice*. 11.
- Downing, J., Powell, R. A., & Mwangi-Powell, F. (2010). Home-based palliative care in sub-Saharan Africa. *Home Healthcare Nurse*, 28(5), 298–307. <https://doi.org/10.1097/NHH.0b013e3181dbf2b6>
- Felicia Marie. (2018). *Integrating palliative care into health systems is essential to achieve Universal Health Coverage—The Lancet Oncology*. [https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(18\)30600-4/fulltext](https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(18)30600-4/fulltext)
- Gomes, B., Calanzani, N., Curiale, V., McCrone, P., & Higginson, I. J. (2013). Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. *Cochrane Database of Systematic Reviews*, 6. <https://doi.org/10.1002/14651858.CD007760.pub2>
- Government of Malawi Ministry of Health. (2011). *National Palliative Care Guidelines*. 29.
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24(2), 105–112. <https://doi.org/10.1016/j.nedt.2003.10.001>
- Grant, L., Brown, J., Leng, M., Bettega, N., & Murray, S. A. (2011). Palliative care making a difference in rural Uganda, Kenya and Malawi: Three rapid evaluation field studies. *BMC Palliative Care*, 10(1), 8. <https://doi.org/10.1186/1472-684X-10-8>
- Green, J., & Thorogood, N. (2018). *Qualitative Methods for Health Research*. SAGE.
- Harding, D. R. (2007). *PAIN RELIEVING DRUGS IN 12 AFRICAN PEPFAR COUNTRIES*: 48.
- Harding, R., & Higginson, I. J. (2005). Palliative care in sub-Saharan Africa. *Lancet (London, England)*, 365(9475), 1971–1977. [https://doi.org/10.1016/S0140-6736\(05\)66666-4](https://doi.org/10.1016/S0140-6736(05)66666-4)
- Harding, R., Selman, L., Powell, R. A., Namisango, E., Downing, J., Merriman, A., Ali, Z., Gikaara, N., Gwyther, L., & Higginson, I. (2013). Research into palliative care in sub-Saharan Africa. *The Lancet Oncology*, 14(4), e183–e188. [https://doi.org/10.1016/S1470-2045\(12\)70396-0](https://doi.org/10.1016/S1470-2045(12)70396-0)
- Herce, M. E., Elmore, S. N., Kalanga, N., Keck, J. W., Wroe, E. B., Phiri, A., Mayfield, A., Chingoli, F., Beste, J. A., Tengatenga, L., Bazile, J., Krakauer, E. L., & Rigodon, J. (2014). Assessing

- and Responding to Palliative Care Needs in Rural Sub-Saharan Africa: Results from a Model Intervention and Situation Analysis in Malawi. *PLoS ONE*, 9(10), e110457. <https://doi.org/10.1371/journal.pone.0110457>
- Human Rights Watch. (n.d.). *Palliative care and access to controlled medicines*. www.hrw.org/node/86033
- (ICESCR) Article 12.1. (1996). *International Covenant on Economic, Social and Cultural Rights*.
- Jagwe, J., & Merriman, A. (2007). Uganda: Delivering Analgesia in Rural Africa: Opioid Availability and Nurse Prescribing. *Journal of Pain and Symptom Management*, 33(5), 547–551. <https://doi.org/10.1016/j.jpainsymman.2007.02.014>
- Johnston, G., & Abraham, C. (1995). The WHO objectives for palliative care: To what extent are we achieving them? *Palliative Medicine*, 9(2), 123–137. <https://doi.org/10.1177/026921639500900203>
- Kale, S. S. (2011). Perspectives on spiritual care at Hospice Africa Uganda. *International Journal of Palliative Nursing*, 17(4), 177–182. <https://doi.org/10.12968/ijpn.2011.17.4.177>
- Knaul, F. M., Farmer, P. E., Krakauer, E. L., De Lima, L., Bhadelia, A., Jiang Kwete, X., Arreola-Ornelas, H., Gómez-Dantés, O., Rodriguez, N. M., Alleyne, G. A. O., Connor, S. R., Hunter, D. J., Lohman, D., Radbruch, L., del Rocío Sáenz Madrigal, M., Atun, R., Foley, K. M., Frenk, J., Jamison, D. T., ... Zimmerman, C. (2018). Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: The Lancet Commission report. *The Lancet*, 391(10128), 1391–1454. [https://doi.org/10.1016/S0140-6736\(17\)32513-8](https://doi.org/10.1016/S0140-6736(17)32513-8)
- Lee, S., & Kristjanson, L. (2003). Human research ethics committees: Issues in palliative care research. *International Journal of Palliative Nursing*, 9(1), 13–18. <https://doi.org/10.12968/ijpn.2003.9.1.11040>
- London Declaration on Cancer Control in Africa*. (2007). http://cancer.iaea.org/documents/May2007_
- Luyirika, E. B., Namisango, E., Garanganga, E., Monjane, L., Ginindza, N., Madonsela, G., & Kiyange, F. (2016). Best practices in developing a national palliative care policy in resource limited settings: Lessons from five African countries. *Ecancermedicalscience*, 10. <https://doi.org/10.3332/ecancer.2016.652>
- Lynch, T., Connor, S., & Clark, D. (2013). Mapping Levels of Palliative Care Development: A Global Update. *Journal of Pain and Symptom Management*, 45(6), 1094–1106. <https://doi.org/10.1016/j.jpainsymman.2012.05.011>
- Malawi Demographics Profile*. (2019). https://www.indexmundi.com/malawi/demographics_profile.html
- Malterud, K. (2001). Qualitative research: Standards, challenges, and guidelines. *The Lancet*, 358(9280), 483–488. [https://doi.org/10.1016/S0140-6736\(01\)05627-6](https://doi.org/10.1016/S0140-6736(01)05627-6)

- Malterud, K. (2012). Systematic text condensation: A strategy for qualitative analysis: *Scandinavian Journal of Public Health*. <https://doi.org/10.1177/1403494812465030>
- Mays, N., & Pope, C. (2000). Assessing quality in qualitative research. *BMJ*, *320*(7226), 50–52. <https://doi.org/10.1136/bmj.320.7226.50>
- Ministry of Health of Malawi. (2004). *Department of Planning A joint programme of work for a health sector wide approach (SWAp), 2004–2010*. Lilongwe: Government of the Republic. http://gametlibrary.worldbank.org/FILES/466_Health%20Sector%20SWAp%20Malawi.pdf
- Mount B. (1997). *The Royal Victoria Hospital palliative care service: A Canadian experience*. In: *Saunders CKR, ed. Hospice care on the international scene*. New York, NY: Springer.
- Murray, S. A., Grant, E., Grant, A., & Kendall, M. (2003). Dying from cancer in developed and developing countries: Lessons from two qualitative interview studies of patients and their carers. *BMJ*, *326*(7385), 368. <https://doi.org/10.1136/bmj.326.7385.368>
- Quality of Death Index*. (2015). Perspectives from The Economist Intelligence Unit (EIU). <https://eiuperspectives.economist.com/healthcare/2015-quality-death-index>
- Rhee, J. Y., Garralda, E., Torrado, C., Blanco, S., Ayala, I., Namisango, E., Luyirika, E., Lima, L. de, Powell, R. A., & Centeno, C. (2017). Palliative care in Africa: A scoping review from 2005–16. *The Lancet Oncology*, *18*(9), e522–e531. [https://doi.org/10.1016/S1470-2045\(17\)30420-5](https://doi.org/10.1016/S1470-2045(17)30420-5)
- Saunders C. (1964). *The symptomatic treatment of incurable malignant disease*. *4*, 68–73.
- Selman, L., Siegert, R. J., Higginson, I. J., Agupio, G., Dinat, N., Downing, J., Gwyther, L., Mashao, T., Mmoledi, K., Moll, T., Sebuyira, L. M., Ikin, B., & Harding, R. (2012). The “Spirit 8” successfully captured spiritual well-being in African palliative care: Factor and Rasch analysis. *Journal of Clinical Epidemiology*, *65*(4), 434–443. <https://doi.org/10.1016/j.jclinepi.2011.09.014>
- Selman, L., Simms, V., Penfold, S., Powell, R. A., Mwangi-Powell, F., Downing, J., Gikaara, N., Munene, G., Higginson, I. J., & Harding, R. (2013). ‘My dreams are shuttered down and it hurts lots’—a qualitative study of palliative care needs and their management by HIV outpatient services in Kenya and Uganda. *BMC Palliative Care*, *12*(1), 35. <https://doi.org/10.1186/1472-684X-12-35>
- Selman, L., Speck, P., Gysels, M., Agupio, G., Dinat, N., Downing, J., Gwyther, L., Mashao, T., Mmoledi, K., Moll, T., Sebuyira, L. M., Ikin, B., Higginson, I. J., & Harding, R. (2013). ‘Peace’ and ‘life worthwhile’ as measures of spiritual well-being in African palliative care: A mixed-methods study. *Health and Quality of Life Outcomes*, *11*(1), 94. <https://doi.org/10.1186/1477-7525-11-94>
- Sepulveda, C., Habiyambere, V., Amandua, J., Borok, M., Kikule, E., Mudanga, B., Ngoma, T., & Solomon, B. (2003). Quality care at the end of life in Africa. *BMJ*, *327*(7408), 209–213. <https://doi.org/10.1136/bmj.327.7408.209>

- Sepulveda C, Marlin A, Yoshida T, & Ullrich A. (2002). Palliative care: The World Health Organization's global perspective. *J Pain Symptom Manage*, 24, 91–96.
- Seymour, J., Payne, S., Reid, D., Sargeant, A., Skilbeck, J., & Smith, P. (2016). Ethical and methodological issues in palliative care studies: The experiences of a research group. *Journal of Research in Nursing*. <https://doi.org/10.1177/174498710501000206>
- Stockdale, A. J., Mitambo, C., Everett, D., Geretti, A. M., & Gordon, M. A. (2018). Epidemiology of hepatitis B, C and D in Malawi: Systematic review. *BMC Infectious Diseases*, 18. <https://doi.org/10.1186/s12879-018-3428-7>
- Tapsfield, J. B., & Jane Bates, M. (2011). Hospital based palliative care in sub-Saharan Africa; a six month review from Malawi. *BMC Palliative Care*, 10(1), 12. <https://doi.org/10.1186/1472-684X-10-12>
- The Korea Declaration. (2005). *Report of the Second Global Summit of National Hospice and Palliative Care Associations, Seoul*. www.thewpca.org/EasysiteWeb/getresource.axd?AssetID=25109&type=Full&servicetype=Attachment
- Toye, F. (2015). 'Not everything that can be counted counts and not everything that counts can be counted' (attributed to Albert Einstein): *British Journal of Pain*. <https://doi.org/10.1177/2049463714565569>
- Tufford, L., & Newman, P. (2012). Bracketing in Qualitative Research. *Qualitative Social Work*, 11(1), 80–96. <https://doi.org/10.1177/1473325010368316>
- UNDP. (2019). *Human Development Reports*. <http://hdr.undp.org/en/countries/profiles/MWI>
- WHO. (1986). *Cancer pain relief*. Geneva: World Health Organization.
- WHO | *Cancer pain relief and palliative care*. Geneva. (1990).
- WHO | Global Health Estimates. (2013). *Causes of Death 2000-2011*. World Health Organization. WHO; World Health Organization. http://www.who.int/healthinfo/global_burden_disease/en/
- WHO Definition of Palliative Care. (2011). WHO. <https://www.who.int/cancer/palliative/definition/en/>
- World Health Organization. (2000). *Achieving balance in national opioids control policy: Guidelines for assessment*. Geneva, Switzerland.
- World Health Organization. (2014). WHO. WHA67.19. *Strengthening of palliative care as a component of comprehensive care throughout the life course*. Geneva.
- World Health Organization. (2016). *Planning and implementing palliative care services: A guide for programme managers*. World Health Organization. <https://apps.who.int/iris/handle/10665/250584>
- WPCA Policy statement on defining palliative care. (2013). www.thewpca.org/EasySiteWeb/GatewayLink.aspx?allid=85177

Zomba, Malawi: National Statistical Office. (2014).

NSO. (2014). Integrated Household Panel Survey 2010-2013: Household Socio-Economic Characteristics Report.

(this page intentionally left blank)