

DISSERTATION

**PERCEPTIONS OF HEALTH CARE WORKERS REGARDING THE NEED FOR
PALLIATIVE CARE SERVICES IN THREE SELECTED HOSPITALS IN
LESOTHO**

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Supervisors:

Mrs Linda Ganca
A/Prof. Liz. Gywther
Dr. Alan Barnard

Division of Palliative Medicine,
Department of Public Health and Family Medicine,
Faculty of Health Sciences, University of Cape Town.

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ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
APCA	African Palliative Care Association
ART	Anti-Retroviral Therapy
CEHAL	Centre for Equal Health Access Lesotho
COHSASA	Council for Health Service Accreditation of Southern Africa
COPD	Chronic Obstructive Pulmonary Disease
EOL	End of life
ESRD	End Stage Renal Disease
HBC	Home Based Care
HCWs	Health Care Workers
HIV	Human Immunodeficiency Virus
HPCA	Hospice Palliative Care Association of South Africa
HREC	Human Research Ethics Committee
ICU	Intensive Care Unit
IRB	Institutional Review Board
MDR/TB	Multiple Drug Resistance/Tuberculosis
MoH	Ministry of Health
NCD	Non-Communicable Disease
NDSP	National Development Strategic Plan
NGO	Non-Governmental Organization
NHSP	National Health Strategic Plan
NPFSPC	National Policy Framework and Strategy for Palliative Care
NSAID	Nonsteroidal anti-inflammatory Drugs
OPD	Out-Patient Department
PC	Palliative Care

PHC	Primary Health Care
PHS	Public Health Strategy
SDGs	Sustainable Development Goals
SICU	Surgical Intensive Care Unit
TB	Tuberculosis
UCT	University of Cape Town
UHC	Universal Health Coverage
UN	United Nation
UNICEF	United Nations International Children's Emergency Fund
USA	United States of America
WHA	World Health Assembly
WHO	World Health Organization

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ABSTRACT

Background: In the last few decades, the increasing upsurge in HIV/AIDS and non-communicable diseases such as heart disease, stroke and cancer as well as aging populations has given rise to the need for PC services in many countries globally, including Lesotho. However, available literature indicates gaps in PC development and integration in Lesotho.

Aim: To explore the perceptions of health care workers regarding the need for PC services in three selected hospitals in Lesotho, with regards to knowledge of PC, the burden of care (especially to healthcare workers), existing PC services and policies which guide availability and access to PC medications.

Objectives: (1) To explore selected health care workers' views on the burden of disease at the hospitals where they work and in Lesotho; (2) To identify knowledge, attitudes and beliefs on PC and linking that to the need for PC provision for patients diagnosed with life threatening conditions; including their families; (3) To determine which conditions in the HCWs' views qualify a patient to receive PC, and (4) To identify whether in the HCWs' views there is adequate development and provision of PC services in the hospitals where they work.

Method: This study used a descriptive research design conducted within a qualitative approach. Individual semi-structured interviews were conducted with 12 research participants in three hospitals in Lesotho. Research participants included medical doctors, pharmacists, social workers and nurses. Data was recorded, transcribed verbatim and analyzed using thematic analysis.

Results: Themes and sub-themes emerged from the data analysis: prevalent palliative care conditions, psycho-social support, referral criteria for palliative care services, palliative care challenges, poor infrastructure and lack of resources, accessibility and affordability of pain medication, and lack of palliative care policies and procedures.

Conclusion: Although each hospital had a different pattern of views and challenges, the same reasons and issues were raised all of which suggests primarily that PC services were at low levels of operation, mostly unorganized and in many instances non-existent in Lesotho. The followings recommendations were presented: 1. Introduction of compulsory entry point education and Continuing Professional Development (CPD) for HCWs 2. Sensitization and advocacy for PC. 3. Adequate funding 4. Availability and accessibility of PC medications and 5. Policies promoting restrictions on prescriptions should be reviewed towards formulation new policies.

CHAPTER 1: INTRODUCTION

1:1 Introduction

“How people die remains in the memory of those who live on.” (Dame Cicely Saunders)

As life expectancy increases and socialisation increases in various ways, people are exposed to numerous risk factors which predispose them to a range of communicable and non-communicable diseases. This results in the healthcare system being over-stretched coping with the burden of these diseases. In Lesotho, this has resulted in a reduction in the gross domestic income (GDI) as the budgetary allocation for healthcare increases³⁵. Despite increased healthcare spending, the pressure on the healthcare system remains overwhelming and poses a serious threat to the quality of the services that are provided.

With the increase in life-threatening and life-limiting conditions, and the associated symptoms such as pain, there is an increasing need for palliative care (PC) services to manage these and other symptoms.^{1, 2} However, there is insufficient evidence of the provision of adequate PC services in the Lesotho healthcare system. In view of the current situation, this study seeks to understand the need for PC services in Lesotho based on the perception of Health Care Workers (HCW). In addition, their views on how to alleviate the burden of diseases and address health challenges in Lesotho will be elicited.

1.2 Background

In the last few decades, the increasing prevalence of chronic diseases such as end-stage organ failure, stroke, diabetes, cancer as well as HIV/AIDS, (which is an infective disease, but it is now managed as a chronic condition), with a simultaneously aging population has given rise to the need for PC services in many countries across the world, including Lesotho. In support of the fundamental human right to accessible and quality health care, the sixty-seventh (67th) World Health Assembly (WHA) of 2014, and the Lancet Commission on Palliative Care and Pain Relief, (2018) endorsed PC as a necessary intervention to improve the quality of life, well-being, comfort and human dignity of all patients with life limiting and life threatening conditions.³ The World Health Organization (WHO) has defined Universal Health Coverage (UHC) as all people having access to health services (including prevention, promotion, treatment, rehabilitation and palliation)

of sufficient quality to be effective while ensuring affordability so that financial impoverishment is avoided.⁴ The WHO recommends that PC must be a part of the treatment spectrum for all patients and should be incorporated early to ensure good symptom control as a rational and humane option after other methods become unsuccessful or the patient decides to discontinue treatment.⁵ The African Palliative Care Association (APCA) states that effective African health care delivery is limited by poor recognition and integration of PC services into health care systems.^{6, 7}

Despite the increased access to analgesics and other treatments such as antiretroviral medication in many African countries, most patients, including children, living with a wide range of conditions including HIV/AIDS still suffer from physical, emotional, social and spiritual difficulties which could be adequately addressed by PC teams.⁸ Palliative care development in Lesotho, as well as many African countries face a number of challenges.^{6, 9} Some of these challenges include lack of assessment skills, diagnostic tools, shortages of chemotherapy and radiotherapy treatments for cancer patients and under-utilisation of opioids for pain. Lesotho does not have a chemotherapy centre despite the fact that cancer is a major contributor to annual death rate.¹⁰ There is also lack of oncology services.¹¹ According to a recent report, patients from Lesotho requiring certain advanced health care services including oncology, are often referred to South Africa.¹² In addition, a 2019 Lesotho ministerial report indicated that three Lesotho patients were referred to Apollo hospital in India for cancer and renal treatments.¹³ These are all patients who would also need PC services. Further constraints to provision of effective PC is inadequate infrastructure which is attributed to insufficient health care funding in many African countries.⁶ Doctors, nurses, pharmacists, social workers and community health workers are some of the healthcare professionals that are central to PC delivery in all healthcare systems. In Lesotho, there are too few healthcare workers (HCWs) attending too many patients, hence the capacity of the healthcare system to function effectively is limited. This limitation also affects adequate numbers of appropriately trained HCWs for PC.¹⁴ Kell *et al.*¹⁵ stated that HCWs are not receiving adequate training required for them to provide PC services in Lesotho clinics and hospitals.

Despite the importance of having trained HCWs providing PC, there is little literature addressing the HCWs' perceptions regarding PC services in Lesotho. Understanding HCWs views and opinions about PC services will be highly beneficial in addressing the need for PC services as well as in the implementation of quality PC services in Lesotho.

The provision of adequate numbers of suitably trained HCWs is key to the integration of PC in any national healthcare system. It is the duty of knowledgeable HCWs to promote a holistic PC approach to the management of patients with life-threatening conditions, especially those in the terminal stages of disease.¹⁶ They need to have knowledge of available policies and procedures on the management of patients requiring PC. These include especially the availability, access to and prescribing of analgesia and opioid medications for pain. Healthcare workers need to understand the influence of psychosocial factors on most patients' end of life suffering and care, as well as the holistic goals of PC in patients' management.¹⁷

This section has provided a general introduction and background to the rationale for this study focussing on the burden of diseases which demonstrate the need for PC, and the responses of the WHO, WHA and APCA for global and African action to provide PC services. It has briefly outlined the challenges to the provision of PC in Lesotho, as well as describing the importance of PC training for HCWs. The subsequent sections of this chapter will provide an overview of PC, models and levels of delivery of PC services, as well as the role of HCWs in providing PC. The state of PC services in Lesotho will be explored in more detail.

1.3 Overview of palliative care

PC has been defined by the WHO as an approach that improves the quality of life of patients with life-threatening conditions, through the prevention and relief of suffering by means of early identification, precise assessment and treatment of pain as well as other health problems, whether physical, psychosocial or spiritual.¹⁰ Therefore, the main goal of PC as a strategic health care intervention is improvement of the quality of life, well-being, comfort and human dignity for patients (especially those suffering from chronic pain and at end of life).^{17, 18} In view of this and given its strategic importance to patients' health, PC services are provided through different models and at different levels of delivery.

1.4 Models and levels of PC services

The driving force that motivates most HCWs is the passion to prevent and alleviate patients' suffering.¹⁹ Demonstrating this passion, Dame Cicely Saunders, a British Doctor founded the first modern hospice in London (circa 1968) with the vision of caring for terminally ill patients. Scholars have attributed the present day development and 'the inclusion of PC to Dame Cicely's hospice efforts.'²⁰ Over decades of PC development, different PC models have been established at different levels of care. For the purpose of this study, five models of PC are identified and discussed. These include 1) home-based PC, 2) mobile outreach services, 3) outpatient care, 4) in-patient care and 5) hospital-based PC teams.

Home-based PC is a model of care provided by community-based HCWs with the support of a palliative care team and the patients' caregivers (family, friends and community members) at their homes. The HCWs offer patients physical, psycho-social and spiritual care as well as appropriate medication and referral services particularly for the elderly. This model represents the most valid option for families in Africa.²¹ A second model is the mobile outreach services **are** operated by PC teams who visit distant health centres and treat patients who are unable to access PC services due to limited access to hospitals.²² The third model is outpatient palliative care. This provides walk-in PC services to out-patients through the professional services of a PC team or other trained HCWs in a clinic.¹²

The fourth model comprises in-patient Care where PC services are provided in a specialist palliative care unit or hospice to patients who are either at the end of life or who are in extreme pain or present with symptoms which cannot be adequately managed in patients' homes.¹² The fifth model is the hospital-based PC provided by a team of PC experts together with a multidisciplinary team who provide consultative services within a hospital setting. The researcher has decided to use these five different models of PC as a useful framework within which to develop the discussion with HCWs in Lesotho.²³

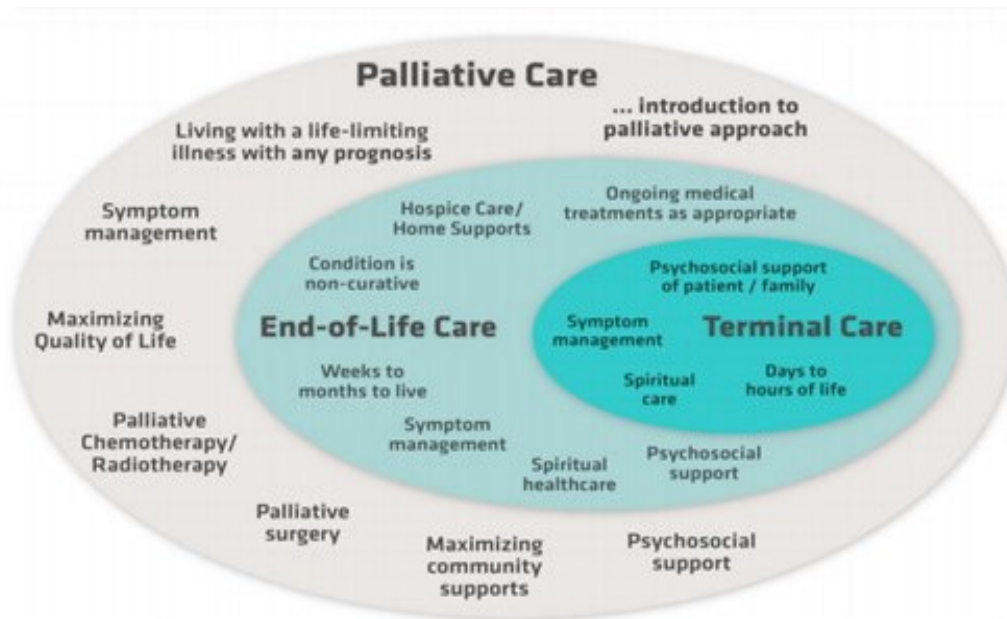
1.5 Levels of PC delivery

In conjunction with the different models of PC explained above, HCWs provide PC through each or all the three levels of PC services identified below. First, the primary PC level is recognized as a fundamental level of PC services offered by all HCWs at all grades of expertise and experience

and across all levels of health care systems and delivery centres. The second level is an intermediate level of PC service also known as the generalist PC level. HCWs (such as general practitioners, nurses, home caregivers), who have had background training and experience on PC services provide non-specialist PC services.²⁴ The third level is the specialist PC level, which is available at specialist hospitals. The HCWs have specialist training in core areas and skills of PC ranging from effective communication, management of symptoms, patients' emotional, spiritual, social and psychological support.²⁵

In addition to the three levels of PC services, there exist phases or layers of care which are applicable at different stages of illness. This process of PC service delivery between the layers are demonstrated in the diagram below (Figure 1.1). The diagram presents the three layers of PC services delivery. The first layer includes providing services for patients living with a life-limiting conditions of any diagnosis. It involves symptom management, maximizing quality of life, palliative treatment, maximizing community support and psychosocial support.²⁶ The second layer is end of life care, which is characterized by non-curative conditions being managed throughout the last days of life, which may be weeks to months before death occurs. It involves Hospice care/home supports, on-going medical treatments as appropriate, symptom management and spiritual care. End of life care includes the progression to terminal care, which happens days to hours before death.²⁷

Figure 1.1 The phases and layers of care



Source: <http://hpc.providencehealthcare.org/about/what-palliative-care>

1.6 Fundamental human right and public health strategy of PC

The United Nations (UN) has included PC services as part of the Right to Health indicating that failure to ensure access to controlled medicines for the relief of pain and suffering threatens the fundamental human right to health and to protection against cruel, inhumane and humiliating treatment.^{28, 29} This validates the importance of PC which improves health care, maintains human dignity, and supports the fundamental human right of access to adequate pain management.³⁰ In spite of this imperative, millions of patients especially those in sub-Saharan Africa still do not enjoy this fundamental right. To address this issue of human right in health care and PC services, the WHO introduced Public Health Strategy (PHS) for PC.¹⁶ The PHS is a “science of protecting and improving the health of people and their communities through the promotion of healthy lifestyles, disease research, detection of, reaction to and prevention of communicable diseases.”³¹ Public health in sub-Saharan Africa, in the last three decades, has not demonstrated these characteristics but has continued to experience major challenges.

The WHO recommends four critical focus areas for successful administration and integration of PC services into national health systems of its member States.^{19, 20} The strategy provides guidance to governments on how to implement PC programs and cancer control programs into national health care systems.¹⁶ The focus of the public health strategy is to incorporate PC as one of the components of comprehensive cancer care^{16, 32} focusing on the four pillars of PC integration, which are, 1) appropriate policies, 2) adequate drug availability, 3) education of HCWs and the public, and 4) implementation of PC services at all levels throughout society.^{16, 33} In order to achieve this strategy, WHO and the World PC Alliance committed their support to all member states in developing PC policies and services.

The WHO public health strategy for PC has been adopted as one of the greatest advocacy measures for the integration of PC services into the mainstream health care delivery throughout all levels of care.³⁴ However, PC has not been well implemented despite the call from several international organizations. The WHO Executive Board's 134th session's provisional agenda item 9.4 of 20th December 2013 urged all member states, including Lesotho to incorporate PC services into their national health systems against the backdrop of waning commitment by nations.^{2, 35} Worldwide, provision of PC has been included in the definition of Universal Health Coverage (UHC).³⁶ However, in Lesotho, lack of adequate access to national basic health care which includes preventive, curative, rehabilitative and PC, hampers the implementation of PC at national level in line with principles of Universal Health Coverage.³⁷

In 2014, the WHA (67.19) directed the WHO and member States to guarantee access to PC services at all health system levels, highlighting the importance of primary health care and community/home-based care which strengthened the provision of PC as a public health strategy.³⁸ The WHA recommended the inclusion of PC in countries' health policies and budgetary allocations as well as indicator-based assessments and monitoring of progress reports on PC.^{3, 26} It also mandated the adequate supply of important PC medicines, and inclusion of PC in the education of health care providers as well as awareness for the public.¹⁶ The Global Action Plan towards prevention and control of Non-Communicable Diseases 2013/2020, included PC as part of the mandatory comprehensive service provision for Non-Communicable Diseases (NCDs).³⁹

The health situation in Lesotho suggests that there is significant need for PC services based on the burden of NCDs and the associated symptoms especially among patients living with life-

threatening conditions.³⁵ The 2015 World Bank report, indicated that NCDs were the cause of 28.7% of deaths in Lesotho,⁴⁰ all of which may have benefitted from PC. Currently, there is no documented evidence that supports the presence of adequate and well-integrated PC services in the country. The WHO have noted that Lesotho would qualify to receive capacity building activities for establishing PC services, even though they have not integrated PC services in the main stream of their national health care systems.⁴¹ They have cited the availability of sensitized personnel, expressions of interest with external organizations, conference participation and visits to hospice and PC organizations as the reasons for listing Lesotho among recipient-countries. Other reasons given by the WHO included Lesotho's preparation of strategy for services development and lobbying of policy makers/health ministry towards integration of PC in the country's health care system.⁴²

At a continental level, the African Ministers of Health adopted the Kampala Declaration on PC on 25 August 2016 at an International Health Conference in Uganda. The declaration allowed the citizens and civil society to hold their governments accountable towards ensuring delivery of quality PC services.⁴³ The Ministers resolved that there must be access to domestic PC services, including analgesics, and collaborative action to ensure an adequate supply of essential medicines in PC. They resolved to reduce shortages, review and revise national and local legislation and policies for controlled medicines. This would be with reference to the WHO policy guidance on improving access to, and rational use of analgesics, in line with the United Nations international drug control conventions.⁴⁴

The next section describes the health situation in Lesotho in relation to PC as a public health strategy and fundamental human right.

1.7 Health situation in Lesotho

The National Health Records in the country indicate that NCDs and communicable diseases are the major causes of morbidity and mortality in Lesotho.¹⁰ Among the top ten causes of morbidity and mortality, are cardiovascular disease, diabetes mellitus, HIV and TB¹² Cancer was reported to have accounted for 4% of all deaths in the country.⁴⁵ The World Bank report of March 2019 indicates that Lesotho has a high prevalence of HIV/AIDS and its TB co-epidemic.⁴⁰ The HIV prevalence rate in Lesotho is at 25% in the adult population (15-49 years), the second-highest in the World.⁴⁴

Besides the burden of these diseases on healthcare provision, the ministerial annual report suggests that the Lesotho national health expenditure does not match the expected key health outcomes.⁴⁰ ⁴⁶ This may be exacerbated by the high costs incurred by government for patients receiving oncology services outside the country. The Lesotho National Ministry of Health (MoH) indicated that in 2018, the total health expenditure was 12.7 per cent of the total national expenditure, ranking second highest after education. Of this, only 7 per cent of the health budget was committed to primary health care with the rest allocated to administration, purchases, salaries and wages.¹³ The UNICEF report on the Lesotho Health Budget 2018/19 indicated that the budget was insufficient and inconsistent.⁴⁴ Therefore, this ‘poor credibility of spending’ in public health is a challenge to achieving public health goals as well as the sustainable development goals linked to public health in the country.³⁴

Despite Lesotho’s appreciable investment in the health care sector, the health situation has not improved much in almost a decade. In the March 2019 budget speech, the Minister of Finance confirmed the increasing prevalence of non-communicable diseases such as cancer in the country. Additionally, the Minister’s urgent call for the establishment of a national chemotherapy centre is a reflection of serious concern about cancer diseases in Lesotho.¹³ However, the establishment of a national chemotherapy centre will not adequately address the need for PC, but will increase the country’s health care expenditure.

Legislation and policies are a key to improving the health situation in Lesotho. There is evidence of strong legal frameworks for national health care delivery. For instance, the Lesotho constitution recognizes ‘health gain as a social gain’. Health gain relates to the status of health of individuals with regard to life expectancy and enhancement of quality of life, while the latter deals with the wider issues concerning quality of life such as extra care and quality of services provided for vulnerable groups such as the elderly and children.¹⁰ Apart from the constitution, health care service delivery in Lesotho is also guided by the National Vision Document (Vision 2020) and the National Development Strategic Plan (NDSP) both of which speak to two critical health plans.^{1, 30} Vision 2020 envisions a healthy nation based on organized and adequately equipped human resources with a main focus of tackling major issues of HIV and AIDS.^{12, 45}

Other important health policy documents in Lesotho include the revised National Health Policy of 2016 and the National Health Strategic Plan (NHSP 2017-22).¹² The NHSP is an ambitious policy

targeting the transformation of Lesotho's economy from a consumer-driven economy to a producer-based economy led by the private sector.^{46, 47} It recognizes the impact of communicable diseases such as HIV/AIDS on the economy. In this regard, the plan seeks to implement Post-2015 UN Sustainable Development Goals and Africa's Agenda 2063. (The Government of Lesotho, National Strategic Development Plan, 2018.19-2022/23).^{10, 48} With the health care policies, Lesotho has demonstrated the willingness to provide PC at a greater capacity, however, implementation has not yet reached its potential peak.

In terms of structure, Lesotho's health sector is organized into three levels of primary, secondary and tertiary health care systems. The country has 372 health facilities, 188 of which are health centres serving as the first contact for patients requiring primary health care services. There are two referral hospitals as well as 18 district hospitals which are supported by three clinics. The two referral hospitals do not have facilities for managing cancer patients.¹⁰ The next section provides a basic overview of PC services in Lesotho.

1.8 PC services in Lesotho

As with many good initiatives, several challenges face the country as it endeavours to integrate PC services into its health care systems. Although there may be some health service institutions providing primary PC services in Lesotho, most patients requiring PC have no access and where available, the services are not adequate, holistic or equitable. The 2014 Lesotho National Health report refers to PC services in the country as erratic.^{10, 45}

There is no known National Association for trained PC health professionals in Lesotho.¹² The African Palliative Care Association (APCA) reported in 2017 that Lesotho is in a process of developing Clinical Guidelines and has a few individuals trained in PC. APCA also mentioned the nomination of one person by Lesotho's MoH to work closely with WHO.⁴⁷ However, more trained individuals and the formal establishment of PC services in Lesotho are required to adequately meet the need for PC.¹² With the high prevalence of life-limiting conditions such as HIV/AIDS, as well as the increasing incidence of NCDs in Lesotho, the integration of PC into the health care services is crucial and can no longer be ignored.⁴⁹

1.9 The role of health care workers in PC services

Health care workers are the link between patients and health care institutions and the services they offer. They provide both prophylactic and curative services in a bid to improve quality health care and play an important role in the effective delivery of health care services.⁶ The WHO has indicated that HCWs are critical to achieving local, national and regional health care goals, including certain Sustainable Development Goals (SDGs). . Capacity building and improved skills of HCWs is vital to achieving these goals. This includes PC service delivery. HCW knowledge, skills, beliefs and attitudes about PC have significant impacts on the nature, extent and quality of PC services administered to patients and families with life-threatening conditions. Studies show that lack of proper awareness and understanding of PC by HCWs may pose a barrier to the effective implementation of quality PC services.⁵ In view of these findings, the perceptions of HCWs regarding PC services in Lesotho, require further investigation.

1.10 Conclusion

This chapter has provided a general insight into the need for the study by focusing on health care systems, increased health care burden of communicable and non-communicable diseases, WHO Public Health Strategy which prioritizes PC as a public health intervention and fundamental human right, the need for integrated PC services and trained HCWs, within a country's national health care system. The chapter also explored the health situation in Lesotho in relation to the current state and need for quality PC services and standard practices.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

The researcher understands a literature review to be an analysis of existing literature to understand what is known and what gaps in knowledge exist. This chapter will assist the researcher to place the significance of his work in the context of what is already known.⁵⁰

This literature review was conducted by using online search engines such as PubMed, Medscape, Google Scholar, academic books, journals, articles, government publications and other international official documents. A preliminary review was undertaken with reference to the research topic key terms, and a variation of these terms were included in the literature search: “Pperception”, “health care workers”, “for palliative care”, “palliative medicine”, “hospice care”, “terminal care”, “end of life care”, “hospital”, and “hospital setting”. The term ‘palliative care’ represented the link in the searches conducted. The exercise revealed that there is little information concerning PC services in Lesotho since only one study (Kell and Walley’s 2009 study) with close similarity has been conducted on this topic in the country.

2.2 Development of PC

In the International Journal of Nursing Studies, Chiang, Chen and Ho explained that in medicine or the medical field, all caregivers are trained to understand from the start that their work deals with reducing patients’ suffering and trying to make them feel better.⁴⁹ In the same vein, the British Doctor, Dame Cicely Saunders started the first hospice with the main focus of caring for the terminally ill patients.⁵¹ Ever since, there has been the development of PC in Europe as well as other countries internationally. Matrojohn, Nanney and Smith explained that the development of PC in Africa started in the 1970s with the establishment of first hospices in Zimbabwe and later in South Africa.⁵²

Grant *et al.* in a a study on PC in Africa, focused on the integration of PC into national health systems in Africa looking at the 3-5-year program for PC integration in 3 hospitals each in Kenya, Rwanda, Uganda and Zambia. Using surveys, interviews and focus groups regarding advocacy, staff training, service delivery strengthening as well as international and regional partnership, the

study showed that some success was achieved in the integration of PC in the selected hospitals through concurrent interventions of these four approaches.

A limitation of the study was that it focussed largely on East Africa. The findings might not be valid for other parts of Africa in terms of PC development. . However, the researchers' conclusions might be relevant to rest of the continent. They recommended that the integration of PC into health care in Africa can be achieved through the delivery of concurrent interventions such as “advocacy at Ministry, Provincial and District level, intensive and wide-ranging training, clinical and support services supported by resources, including essential medicines, and an investment in partnerships between hospital, district and community.”⁵³

Two years after Grant et al.'s study, Clark et al. evaluated the state of PC provision across Africa, mapping the provision of PC services country by country and exploring the perspectives and experiences of key stakeholders. This study was more comprehensive using a multi-method review combining evidence from published and other literature, information from existing public health data; and had a larger representation of African countries, with ethnographic field studies in 7 countries and qualitative interviews with 94 individuals from 14 countries. The study also engaged with hospice and palliative care activists, including clinicians, managers, volunteers, policy makers, and staff of donor organizations in 47 African countries.

While Grant et al. saw progress in PC development, Clark et al found that PC services were largely uncoordinated and fragmented in most African countries, and that coverage of services was limited. Palliative care support and services were provided mainly by NGOs such as funded by donor organisations, especially in 11 of the countries reviewed. There was a scarcity of opioids and PC staff. Palliative care capacity building existed in 11 countries while 4 countries had PC policy development.

Although both studies agreed that there were working models for the development of affordable, sustainable community-based hospice and palliative care services in countries such as in Uganda and Kenya, as well as South Africa and Zimbabwe, the researchers concluded that there was no strong evidence of commitment towards PC development in Africa.

Clark et al.'s study provided a historical background for this proposed study in Lesotho by understanding the development of PC in Africa as well as measuring the growth of the services over two decades. Apart from the countries with some measure of PC development, his study established that little has been achieved over the years in many African countries. Lesotho is one of the countries with a delayed development of PC, compared to South Africa and Botswana which are both in the same region.⁴¹

2.3. Integration of PC into National Health Systems

The WHA adopted Resolution 67.19 recommends that all member States should integrate PC into their health care systems.⁵⁴ and the WHO endorsed a Public Health Strategy (PHS) model to be used to integrate PC into the health care systems.

The implementation of the WHO PHS is affirmed in the study conducted by Grant *et al* regarding the need for PC development and integration at all levels of health care.⁵⁵ In addition, WHO and WHA focused on PC as a core element of health, therefore, policies and budgetary allocations towards development of PC is vital in order to achieve the PHS model.^{18, 39} The PHS was supported by Hogerszeil *et al*'s study which advocated for accessibility of essential PC medicine and indicating that PC must be made an integral part of health care systems.^{56, 57}

The *Global Action Plan towards prevention, and control of Non-Communicable Diseases 2013/2020*, includes PC as part of comprehensive services mandatory for NCD management.³⁵ Similarly, the WHO Executive Board 134th session provisional agenda item 9.4 of 20th December 2013 urged all member states including Lesotho to include PC services in their national health systems.³

Despite all these policy provisions and guidelines, the public health systems in sub-Saharan Africa continue to experience failure to implement PC in the last three decades. This experience has been linked to diverse challenges plaguing the continent. Akala and El-Saharty, state that health outcomes are worse in Africa because of the challenges of health-transition and health-system issues. The authors recommended the “development and deployment of a diverse spectrum of strategy towards effective public health services delivery for African populace.”³²

At a regional level, the Second African Ministers of Health Session on PC in 2016 -The Kampala Declaration-indicates that progress in PC should be determined by the WHO's PHS model. They

also agreed to commit to the Worldwide Hospice Palliative Care Alliance's consensus statement for strengthening PC as a major component of healthcare in Africa as contained in the World Health Assembly's PC Resolution WHA 67.19 of 2014, with reference to its recommendations to WHO member States.^{3, 43} In this regard, the particular focus areas of the WHO PHS includes PC policies, which the WHA states: to develop, to strengthen and to implement where appropriate.^{7,}

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2.4 Policies on PC

The key success in establishing PC services is the appropriate and attainable policies on PC at all levels of care.^{7, 58} Harding *et al* studied the importance of policies and their role in becoming the major driving force for implementation of PC services into health care systems.⁵⁹ The researchers discovered that while the field of palliative care has been established in sub-Saharan Africa through collaborative efforts by clinicians, advocates, governments, and communities, there was still a major global challenge, especially with HIV medicine, to exert influence and deliver palliative care to patients. Advocacy has also improved through the use of robust locally relevant evidence.

Tumura and Manjula⁶⁰ in their commentary on *Five Policies to Promote Palliative Care for Patients with ESRD*, discussed extensively the importance of PC policies in the development of such care at national and international level. The authors argued that PC policies would encourage care for patients with life-limiting conditions, address the lack of access to PC, lack of capacity to deliver PC, and lack of evidence of PC. Therefore, strengthening of PC policies should be of utmost importance in national health reforms. Tumura and Manjula's study provides supporting evidence for this study which has as its thematic focus, the perception of health care workers, directly relates to access to PC and capacity to deliver PC.

Schreibeis *et al.*,⁶¹ in a study conducted in the United States of America, identified challenges and potential solutions for promoting, adopting, and implementing policies that would support high-quality PC using semi-structured interviews. The study revealed that knowledge of PC in the healthcare sector, cultural beliefs about PC, financing of PC services and public awareness of PC were major challenges to development of PC. The researchers emphasised that to promote PC in any given setting, there is need for consensus building among stakeholders, knowledge of how to advance a PC policy agenda to develop a PC policy. Schreibeis *et al.*,⁶¹ provide additional evidence

for this current study since it identified similar issues of perceptions such as HCW's knowledge of PC, as important.

According to a study published in the American Society of Clinical Oncology Journal on PC development in Africa with a focus on Uganda and Kenya, it was revealed that less than 5% of people in need of PC services are able to receive it and this in the light of the fact that it is estimated that by the year 2050, the incidence of cancer will rise 400% of the current situation worldwide.⁶²

In order to develop PC to meet this increasing need, it is important to have effective policies in place. In this regard, the WHO has observed that some of the existing policies in some African countries are inadequate because they do not include integration of access to pain medication. Consequently, patients who require PC services continue to suffer from unrelieved pain because of inadequate provision for pain relief in local health policies.⁶³ However, some countries such as Zimbabwe, Tanzania, Swaziland and Rwanda have policies where access to pain medication has been improved.⁹

2.5 Barriers to Opioid Use among Patients requiring PC

According to the Worldwide Hospice Palliative Care Alliance (WHPCA- 2014), quality PC cannot be delivered without the presence and accessibility of essential PC medicine particularly opioids.² Globally, WHPCA indicates that access to these analgesics is poor and it is estimated that 83% of countries have low to non-existing access to opioids. 4% of these countries have moderate access, 7% have adequate access while, 6% have no data available.⁶⁴

The African Palliative Care Association (APCA), to promote relevant PC in Africa developed a document titled, '*APCA standards for providing quality palliative care across Africa*' (2020), through the review of existing PC standards across Africa. In the review, the group identified that PC medicine availability and accessibility are crucial for the effective and appropriate pain and symptom control.⁷ However, contrary to WHO recommendation that all countries must formulate and implement a comprehensive national medicines policy; PC medicine remains unavailable (especially opioids) in most parts of the world particularly in Africa. WHO's position is that one of the major obstacles to PC medicine is the strict regulations that limit availability and accessibility of the medication.⁶⁵

Besides inflexibility of some policies regarding pain medications, the Open Society Foundation affirms that another major obstacle to opioid availability is that professionals fear being prosecuted for what may be interpreted as over-prescription of opioid medication as a controlled substance.⁵⁷ Even though, sensible regulation of medication like morphine and other opioids is essential, over-regulation has been unnecessarily detrimental to patients' quality of life.²⁸

The United Nations (UN) indicates that the failure to ensure access to controlled medicines for the relief of pain and suffering threatens the fundamental human right to health and protection against cruel, inhumane and humiliating treatment.^{29, 57} Therefore, making progress on the provision of PC medication strict regulations on prescribers have to be reviewed to make opioids available and accessible at all levels of care for PC.

Dungu discussed in the British Medical Journal which PC approaches are suitable in developing countries. The report revealed that morphine is said to be the most appropriate medication for moderate to severe pain relief. However, access to morphine remains very poor in Africa. Although, evidence shows that morphine is inexpensive, safe and effective,^{18, 66} consumption is far below the global mean.

Access to pain treatment as a fundamental human right is another discourse that has been advanced by some scholars. Namisango et al. reflected that it is a fundamental human right of patients with severe pain to have access to pain-alleviating medicines. However, the authors claimed that the enjoyment of this right is hardly guaranteed for patients across Africa.⁶⁷ For instance, in many countries in sub-Saharan Africa, availability and access to medication such as opioids are disrupted by strict government regulations, poor pharmaceutical systems and weak supply chain management.⁶⁸

From studies reviewed under this section, some of the key points highlighted are that quality PC cannot be delivered without the provision of and accessibility to essential PC medication, particularly opioids. More so, opioids remain unavailable in most parts of the world and particularly in Africa. To ensure that PC medication including opioids are available and accessible at all levels of care, countries need to remove strict regulations on prescribers.

2.6 Education and training in PC

Globally, education is key to the development and advocacy of PC at all levels of health care. Lack of knowledge on PC inhibits the progress in advancing PC services at national level through to the lowest level of health care.⁶⁸ Similarly, as Aldridge stated, inadequate education and training pose serious threats to the integration of PC in countries' health care systems.⁶⁸ Training in PC is critical and need to be included in the management of patients with HIV, cancer, heart disease, COPD and other chronic life limiting conditions,⁶⁹ and the increased incidences of life-limiting conditions such as cancer and HIV/AIDS in Africa has led to an increase in the need for PC education and training as an essential component for improving patients' quality of life in both adults and children.⁷⁰

The WHO PHS states that education and training in PC are key in delivering effective quality PC services. Therefore, PC training must be viewed as vital to supporting health care workers and the public in implementation of PC.²⁶ In this regard, WHO suggested that PC training must be included in the educational curriculum of all health professionals at all levels of their study.⁷⁰ As many African countries are experiencing high levels of HIV/AIDS and cancer, some of them have started considering the need to implement the WHO proposal.

In Sub-Saharan Africa and in many other parts of the World, education and advocacy for the implementation of PC is highly important in communities as well as in the health care sector.⁹ African countries resolved through the Kampala declaration of 2016 to include PC as an integral component of the ongoing education and training offered to care providers in accordance with their roles and responsibilities.⁷ In this regard, countries such as Kenya have shown strong political will by integrating PC training into the Colleges and Universities curricula across the country.²⁴ Apart from Kenya, Grant *et al.*'s 2016 study findings indicates that four other African countries namely Uganda, Zambia, South Africa, and Rwanda have incorporated PC into health care workers' training and education curriculum. In 1993 and 1994, Uganda through Hospice Africa, introduced PC training to clinicians and nurses as well as in medical schools across the country. In this regard, Uganda is acknowledged as one of the countries in Sub-Saharan Africa to have attained three critical components of an effective PHS⁷¹ Palliative Care is also a component of the undergraduate medical programme curriculum at the University of Zambia and Moi University in Kenya.

In South Africa, there is a postgraduate palliative medicine teaching program at the University of Cape Town (UCT). PC is also taught at the undergraduate level in the University of Cape Town, the Wits University, where a unit is dedicated to PC, as well as at some other universities to varying degrees. Tanzania has shown progress by recognizing the significance of education and training towards improving health care workers' capacity in providing PC services by including PC into the nursing curriculum.³⁸ Kenya, Malawi, South Africa and Uganda have all accredited PC as an examinable academic course in some of their educational institutions.^{55, 72}

2.7 Funding for PC

In a report published in the Journal of Palliative Medicine, Groeneveld *et al.*, investigated a funding model in PC. The authors argued that funding for PC is essential if PC is to be well integrated in the mainstream health care systems.⁷³ For instance, availability of funds to support the carers may help to reduce the need for patient hospital admissions.⁷⁴

Keim-malpass *et al.*, in their article in a US Journal of Paediatric Health Care, examined the coverage of palliative and hospice care for paediatric patients with life-limiting conditions in several States of the United States. The authors found that the State law regarding funding for paediatric PC and its benefit makes provision for training of health care workers, development and implementation of PC services.⁷⁵

2.8 The Concept of Perception

Perception is a key concept of this study. Therefore, it is important to understand the concept to achieve the objective of this study. According to Lewis 2011, the etymological foundation of the word perception is found in the Latin word- *perception* and *percipio*, meaning 'to physically or mentally take possession or to seize'. Also, the 6th edition of the Advanced Learner's dictionary defines perception as "an idea, a belief or an image you have as a result of how you see or understanding something."⁷⁴

Lindsay and Norman defined perception as "the process of recognizing (being aware of), organizing (gathering and storing), and interpreting (binding to knowledge) sensory information."⁷⁶ In other words, perception is "the system by which human beings makes sense of their environment and what is happening in it."⁷⁷

Furthermore, McDonald presented a concept analysis of perception from the viewpoint of nurses in by attempting to define, describe, and delimit the concept of perception using nursing literature from Medline data. She described perception as a way an individual sees the world around him/her; a ‘uniquely individualised experience.’ In other words, perception is subjective. Other definitions of perception are also investigated through the viewpoints of different fields of knowledge. In physiology, perception is concerned with “the neurons that enact it”. In psychology, perception is defined as “an organisation or processing of sensory information into meaningful experiences”.⁷⁶

Overall, McDonald’s synthesised definition of perception captures three major elements of a way of seeing a phenomenon, processing or understanding of a stimulus and integrating of memories and experiences in the process of making meaning. The researcher concluded that perception can impact clinical practices, such that nurses should be aware of how perceptual differences impact the delivery of nursing services.

From the studies analysed above, it is obvious that perception is multifaceted and complex having layers of meanings from one discipline to another. However, several relevant meanings or themes similar in concept to perception are idea, a belief or an image, knowledge, understanding, interpretation, meaning, attribution, perspectives, opinions, attitudes and experience. More importantly, perception is a “confluence of phenomena, stimuli and process of making meaning for an individual or group”.⁷⁶

2.9 Perceptions of PC among Health Care Workers

Across the world, it has become an important practice for policy-makers and researchers to seek the views of patients and health care workers in the planning, development, review and evaluation of PC services.⁷⁸ Many studies have been conducted in the field of PC with the aim of understanding how patients and health care workers perceive PC. Most studies about or related to the issue of perceptions of palliative usually focus on perceptions of patients and/or family carer or perceptions of PC by health care workers, while some have a mixed focus group combining patients, families, health care workers and community members.

Some recent studies have tested the relationship of perception to effective delivery of PC. For instance, Aldridge *et al.* conducted a literature review education, implementation, and policy

barriers to integration of PC between 2005-2015 using PubMed and data from 405 hospitals. They analysed barriers to PC integration against the WHO's framework for PHS for PC. The researchers found that many study results indicated that one of the major barriers to full integration of PC in the United States is the perception of PC as equivalent to end-of-life care by health care workers.⁶⁸ Various misperceptions were noted. For example, some health care workers considered PC as symptom management for patients with life-limiting conditions.

These professionals thought PC was necessary only after 'disease modifying treatment' had ended. Some of the studies reviewed show perceptual problems associated with the use and meaning of professional terminologies of "PC" and "hospice".⁶⁸ The studies revealed that 140 medical oncologists and mid-level providers found the use of the words "PC" disturbing as it invoked a sense of hopelessness in patients and families compared to use of "supportive care." As such, these health professionals preferred the term "supportive care." Aldridge *et al.* added that education plays an important role in shaping the perception of health care workers.⁶⁸ They argued that such perception-related barriers can be addressed with public health education as well as clinical and professional training. Although the studies reviewed by Aldridge *et al* were conducted in the US, yet their findings resonate with the African situation where many health care workers providing primary level of PC have little or no prior professional education in PC. Literature suggest that, many African health care workers have little or no exposure to clinical practices in PC.^{55, 79} In this regard, lack of PC education and training may affect affects HCWs perception of PC services as this has also been linked to misperception among HCWS.

In Montgomery's study of experienced paediatric oncology nurses, the researcher focused on the interactions between children, families, and nurses within the PC and EOL relationship. This was a study of perceptions of health care workers of child-patients focusing on interpersonal communication.²³ Communication is essential to the nurse-patient relationship and requires a degree of trust and is affected by the individual attitudes and values the nurse brings into the relationship. In this regard, nurses' perception of PC and patients is key in nurse-patient communication. As McDonald noted, perception can act drive health actions that impact on health outcomes. In this regard, the nurse's perception of care must take into account how patients also perceive health actions or care to be, or being delivered by the health care workers.

Montgomery's study populations included patients, family carers, health care workers as well as community members and leaders in rural areas of the three countries. In terms of experience-oriented perception, the researcher reported that patients perceived PC services provided to them as treatment of dignity and respect in the face of their worsening health conditions.⁸⁰ Health care workers and other carers indicated a stressful but rewarding experience of PC. This indicates that health care workers' perception of their roles or services may point to the fact that positive perceptions may lead to positive experiences.

Using existing electronic literature, the Montgomery's study sought to synthesize qualitative research on EOL care in sub-Saharan Africa to inform policy, practice and further research. The study included Lesotho and other countries such as South Africa, Kenya, Uganda, Zambia, Tanzania, Botswana, Malawi, Congo, Ghana and Togo. Study respondents included health professionals, informal carers, patients, community members and bereaved relatives. The authors gave some insight into the perception of health professionals in PC services. Health professionals reported that working with high numbers of palliative patients in poorly resourced and high-risk situations was challenging for them. The results were cases of fatigue and decreasing expertise among health professionals. PC was seen as high burden of care for the health professionals.⁸¹

While health care workers may perceive the need for palliative care services, their perception of the burden of care may impact its effectiveness and delivery. Recommendations from the literature by Gysels *et al* prioritised improved training for health care workers in management of symptoms, healthy hygiene, clinical care, infection control as well as the development or improvement of professional training programs such as generalist EoL care training, which should include stress management, basic communication and counselling.⁸¹ Kell and Walley's study investigated the perception of nurses with and their general opinions regarding PC for HIV patients in view of the availability of antiretroviral therapy.¹⁵ The researchers used semi-structured interviews conducted with six key informants and ten nurses.

Of all the studies mentioned above, Kell and Walley is most relevant to the current study being conducted by the researcher in terms of its study population which is Lesotho. However, the study has the following limitations: 1) it was conducted at a time (2009) when PC was relatively unknown in Lesotho. According to the researchers, "PC has only recently been introduced. There is thus no coordinating organisation and the MoH had not yet appointed a full-time PC lead,"¹⁵ 2)

the study is relatively old having been conducted over 10 years ago when the Lesotho government was beginning to initiate the incorporation of PC into its national public health systems, and 3) the study limited its scope in by excluding other chronic diseases such as tuberculosis and cancers which were prevalent at the time of their study as well excluding other care workers such as doctors, pharmacists and social workers. Considering healthcare perspectives of palliative care services, Kell and Walley's study found that nurses described palliative care as synonymous with chronic care and felt that palliative care is necessary for HIV-positive patients despite the introduction of ART. However, the researchers advocated that there was need for a greater understanding of palliative care amongst health workers and more commitment from Lesotho based on the findings that nurses had limited understanding of PC.

The study sought to document any change in perceptions of PC since the Kell and Walley's study in 2009¹⁵ of nurses in Lesotho, but including a wider category of HCWs including doctors, pharmacists and social workers. It also broadened the perspective beyond the management of HIV/AIDS management to other chronic health conditions such as diabetes and cancers. Understanding the perceptions of HCWs in Lesotho, will guide the response to any identified need for education, health systems improvement, or advocacy in the implementation of PC. The successful integration of PC at all levels of care, must take into cognisance the aspects of diverse perceptions of HCWs, their impact and factors that influence PC service delivery among health care workers.

2.10 Factors influencing perceptions of palliative care among health care workers

Professional education is a major factor influencing the perceptions of health care workers concerning PC and its delivery.⁸⁰ Montgomery revealed that nurses and other health care providers who participated in her study believed that they were poorly prepared to provide quality PC services to patients.²³ They needed specialised professional education to develop their knowledge and skills in PC, which emphasises the importance of education and continuous professional development in influencing and improving health care workers' perception about PC. For instance, Grant *et al*,⁸² reported that caregivers received training on family planning, health promotion, drafting of wills and use of herbal medicines and this training added to their effectiveness in the community in a similar way to boosting the confidence of the team in relation to PC delivery. Aldridge *et al*.⁶⁸ noted that entry level and continuous professional education is essential to

improving perception of PC among health care workers as well as resulting in overall improvement in PC services.

Adriaansen et al.⁸³ discovered that nurses who receive a postgraduate qualification in PC provide better pain management for PC patients. Other indicated an improved confidence of nurses in managing pain and symptoms after attending courses in PC.^{84, 85}

In the case study of Grant *et al*, poverty strongly influenced perceptions of both patients and HCWs. Particularly, the HCW's experience was shaped by the poverty of the patients and their community. Yet, Grant *et al.*'s study concludes that holistic PC can be provided effectively even within the confines of poverty.⁸⁶ This means that poverty is not an insurmountable barrier to the provision of PC. As the researcher discovered, the delivery context and the different models of PC in the three selected areas of this study did not have a significant influence on perception of patients and caregivers because the experiences and challenges were similar across all the three case studies. The context of delivery and different models of PC are important in shaping perception of health care workers and public health strategy must include equitable provision of services to accommodate different groups of patients and chronic diseases.⁸²

Ethnic and cultural diversity cannot be overlooked in the provision of PC services as they strongly influence perceptions, relating to others and interaction with the environment. PC providers are themselves products of different cultural milieu.⁷⁸ For instance, cultures and religions have different beliefs and practices about life issues such as pain, death, burial and mourning rites.⁸¹ These cultural beliefs might affect understanding and decisions regarding pain management and caring for EOL patients. Relating with patients from different cultural backgrounds poses difficult challenges to perception resulting in or manifesting as stereotyping, generalisations, profiling, making assumptions and bias. Language may also influence perception of PC. For instance, language diversity was cited as major problem in the study of PC among health care workers and patients in Singapore.^{81, 87}

Numerous factors affect the way healthcare professionals perceive PC. Professional education, continuous training, culture, religion as well as clinical and life experiences are some of the factors that shape individual health care professional's perception of PC services and its delivery. The next section discusses some of the major impacts of perception of PC services among health care workers.

2.11 Impacts of PC Services on the HCW

Health care workers such as nurses, pharmacists, social workers and doctors spend a lot of time with patients receiving PC for chronic sickness and end-of-life cases.⁸⁸ Therefore, their perceptions of PC have will impact both patients and PC services delivery.⁸⁹ Grant *et al.*⁸² reports that a PC team positively affected patients and their communities because the team was able to share knowledge about illnesses, stimulated interest in accessing services and encouraged attitudinal change regarding dying among community members. Nurses observed in the study also expressed how PC helped them to better appreciate pain among patients and their role in fostering hope in dying patients especially those abandoned.⁹⁰

Rodin *et al.* considered the perception of nurses and doctors regarding their role of giving spiritual care to patients and how their perceptions influence the performance of this role.⁹¹ The study revealed that nurses would most likely see themselves as having the responsibility to provide spiritual care to patients. In effect, doctors may not likely provide spiritual care since they do not view it as part of their responsibilities in PC services. Doctors, however, may adopt this role if they are spiritually or religious inclined. The study also indicates that doctors who viewed spiritual care as part of their responsibility provided more spiritual care to their patients than those who did not. In essence, the perception of spiritual care in PC services among nurses and doctors impacts on whether they will provide such service and to what degree the service will be provided.⁹²

Sinclair's 2011 study examined how healthcare professionals experience dying and death in PC services and how these experiences impact their clinical practices and personal lives. The study finds that constant exposure to dying and death helps health care workers have a better appreciation of life, develop a spiritual outlook, deep reflection on mortality and continuity of life.⁹³ As a result, such health care workers are able to relate well with their PC patients, show more empathy and a better sense of duty.

In contrast to the above, other studies have reported negative outcomes with healthcare workers' experiences of dying and death. Many nurses and doctors have reported job stress, burnt-out syndrome and job dissatisfaction as a result of their experiencing dying and death among PC patients.^{90, 94} To this group of health care workers, PC is perceived as a distressing job and the workplace as negative and stressful.⁹² Therefore, the delivery of quality PC services to patients are

badly affected by such perceptions. As McDonald advised, it is important to understand the uniqueness of individual's perception and how perception is shaped in order to improve health outcomes for patients. This is point is very critical to PC service delivery where HCWs and patient relationships can be fragile because of the nature and burden of the health conditions requiring palliation.

This section has highlighted some of the major impacts that the perception of health care workers about PC can have on their work and personal lives. Again, it has been established that the perception of health care workers does not only affect themselves, it also affects the patients as well as the quality of PC services provided. In addition, these impacts may be positive or negative for health care workers, patients as well as delivery of PC services.

2.12 Conclusion

In this chapter, the researcher has engaged with issues such as the development of palliative care, public health strategy in PC, PC policies as well as perceptions of PC. Public health and the development of PC in Africa have been slowed by many challenges. Yet, there has been exemplary successes in countries such Kenya, South Africa, Zambia and Uganda. Researchers have recommended concurrent interventions, education, training and understanding of PC policy as well as the development and deployment of a diverse spectrum of strategy towards effective public health services delivery for the African populace

Perception is the central theme of this study. The literature review has shown that there are diverse perceptions of PC which in turn has diverse impacts on HCWs. For PC integration to be successful at all levels of care, training and regulation must take into cognisance the aspect of perception and factors that affect perception of PC among health care workers.

The next chapter outlines the research methodology of this study. The chapter provides information on the use of qualitative methods within a phenomenological approach in three hospitals in Lesotho. It also explains methods of data collection and analysis.

2.13 Rationale for the study

Health care workers such as nurses, pharmacists, doctors and social workers play an important role in the effective palliative care services delivery mainly because of their direct and constant

involvement with patients and their family members. Knowledge, skills, beliefs and attitudes about palliative care among health care workers have significant impact on the nature and quality of palliative care provided and received by patients and their family members. At the present moment COVID-19 pandemic makes even more complicated to many HCWs from various disciplines as they will be immersed in the care of seriously ill patients diagnosed with COVID-19. HCWs will not only be faced with difficulties in managing acute symptoms but also the need to managed patients and family's emotional distress through sound and better communication skills so that patient and family members receive kindhearted and respectable care. PC must be offered to all patients and their family members even when the curative interventions are used since every patient need emotional support, comfort and sound symptom control. Therefore, HCWs must be prepared with necessary skills that they need to deliver this care. The existing COVID-19 wave has revealed this to be true. Also, study findings have shown that lack of awareness among health professionals may serve as a barrier to improvement of access to palliative care.^{16, 18}

The health situation in Lesotho indicates that PC services are urgently needed. PC services will not only assist in reducing patients' suffering but will also relieve pain and other symptoms related to life-limiting conditions as well as to manage medication side effects and toxicity, including anti-retroviral medications.⁴⁸

There is little published evidence on the availability of palliative care services in Lesotho. Many patients needing oncology services are sent out of the country to receive such services. On their return, they do not receive adequate relief of suffering because they are left in the care of family members who do not have experience or training in palliative care. Also, non-availability of palliative care services in the country can be linked to the gaps in knowledge and attitude among health care professionals in relation to palliative care management and service delivery in Lesotho. This study therefore seeks to explore the perceptions of HCWs and its effect on the need for palliative care services in the selected hospitals.

2.14 Research question

What are the perceptions of health care workers regarding the need for developing and implementing palliative care services in three selected hospitals in Lesotho?

2.15 Aim and Objectives

2.15.1 Aim

To explore the perceptions of health care workers regarding the need for PC services in three selected hospitals in Lesotho, with regards to knowledge of PC, the burden of care (especially to healthcare workers), existing PC services and policies which guide availability and access to PC medications.

2.15.2 Objectives:

1. To explore selected health care workers' views on the burden of disease at the hospitals where they work and in Lesotho.
2. To identify PC policies and procedures available in the hospitals
3. To identify the need for palliative care provision for patients diagnosed with life threatening conditions including their families.
4. To determine which conditions in the HCWs' views qualify a patient to receive palliative care and if there is PC services in the hospitals they work.
5. To identify knowledge, attitudes and beliefs on palliative care

CHAPTER 3: RESEARCH METHODOLOGY

3.1 Introduction

This chapter explains how qualitative research method was used to ensure credibility and trustworthiness of the study and how the researcher went about collecting data to address the research question. Research methodology refers “to how the study was done and the reactions, assumptions and methods used to operationalize the study”.^{95, 96} The research question. *What are the perceptions of health care workers regarding the need for palliative care in Lesotho?* Topics to be discussed include research design, study sites, sampling method, sample size, inclusion and exclusion criteria, data collection tools, data collection process, data analysis and how data was stored.

3.2 Study design:

This study used a descriptive research design conducted through the use of qualitative methods. A descriptive design was appropriate for this study as it is used to explore and understand the meaning that people give to their experiences, social context, values, opinion, and behaviours.

A qualitative approach was selected for this study basically because of the nature of the research question. “The nature of this study required an explanation of in-depth perceptions and views on the particular topic to be elicited which would have been constrained if conducted within a quantitative approach”.⁹⁷

3.3 Study sites

This study was conducted in three hospitals in Lesotho namely: Queen Mamohato Memorial Hospital, Saint James Mission Hospital and the Centre for Equal Health Access Lesotho (CEHAL) Hospital. These hospitals were purposively selected because of their locations, the kind of services they provide, availability of HCWs who holds different professions and the role they play in their workplace and the type of patients they deal with on daily basis.

3.4 Study population

This study was carried out among HCWs working in the selected hospitals. They include doctors, nurses, social workers and pharmacists.

3.5 Selection criteria (Inclusion criteria & Exclusion criteria)

3.5.1 Inclusion criteria

- Doctors and nurses currently working in the General Medical Ward and have been working in that same department for more than one year.
- Pharmacists and social workers currently employed by the hospitals under study and have been working for more than one year.
- HCWs who can comfortably speak and understand English language.

3.5.2 Exclusion criteria

- Doctors, nurses, pharmacists and social workers who have been working less than a year at the selected hospitals.
- Interns and HCWs under training and those not involved with patient care.

3.6 Sampling Method

Purposive sampling⁹⁸ was used for this study “as it is a suitable sampling method for selecting research participants who have specific characteristics required for the study being conducted”. The doctors, nurses, social workers and pharmacists were purposively selected for this study as they have experience in patient care, knowledge and/or skills of working in the medical ward. Participation depended on the staff structure and their willingness to participate in the study.

3.7 Sample size

A convenient sample of 12 to 18 participants were selected interviewing about 4 to 6 participants per hospital until data saturation was reached.

3.8 Recruitment of participants

Recruitment started after the study had received ethics approval from the University of Cape Town’s (UCT) Human Research Ethics Committee (HREC) (Appendix A) and permission to conduct the study at the three hospitals had been obtained from the Lesotho National Ministry of Health.

The researcher, via emails which were followed up telephonically, contacted the heads of the three hospitals to introduce himself, inform them of the study and request to conduct the study in their hospitals. The hospital heads referred the researcher to the relevant departmental managers.

After meeting departmental managers and informing them about the study, the managers allowed the researcher to present the study topic to the team during their clinical meetings. The meetings were held in the medical department in each hospital. The researcher presented the study topic, distributed information sheets to the eligible participants and invited them to participate in the study. Eligible participants voluntarily approached the researcher after the meeting and others later expressed their interest to participate in the study telephonically. In the first hospital, 3 nurses, 2 doctors, 1 pharmacist and 1 social worker showed willingness to participate. In the second hospital all 4 nurses, 1 doctor 1 pharmacist and 1 social worker enrolled for the study. But unfortunately, inclusion criteria excluded some of these eligible participants from participating. In the third hospital, 4 nurses, 1 doctor 1 pharmacist and 2 social workers indicated the willingness to participate in the study but during the interview period 3 nurses had left for training and 1 social worker decided not to participate.

After participants had agreed to take part in the study, the researcher, via email or telephone, scheduled an interview date and time with the participants at a private venue most convenient for him/her. All eligible participants offered to provide private interviewing spaces in their respective departments.

3.9 Data Collection tool

The data was collected using semi-structured interviews directed by an interview guide (Appendix F) which was developed by employing open-ended questions to guide the flow of the interview. Open-ended questions allowed the researcher to obtain thick descriptive information and subjective views of participants yet guided participants to openly share their opinions in relation to the topic under study. A Digital recorder was used for recording as it captured the exact words spoken during the interview. The use of the Digital recorder ensured that the researcher was also able to maintain eye contact with participants and pay attention to what they were saying without

being distracted by taking notes. Field notes were compiled in August 2019 by the researcher who captured observations and reflections made during the data collection process.

To confirm that data collection tools were considered trustworthy,⁹⁹ the researcher conducted a literature review and discussed the tools with experts in the field before using them in the main study. The researcher piloted the tool on two willing participants who understood the context but were not included in the main sample for the study. As a result of this pilot, minor changes were made to the interview guide. Data saturation is a methodological principle in qualitative research which occurs when there is no new data, no new themes, no new coding, and ability to replicate a study (Guest, Bunce, & Johnson, 2006 in Fusch, P. I and Ness, L.R.). In line with objectives of the research, I sought mainly to understand the knowledge and attitudes of health care workers regarding PC services, PC health conditions and PC patients. Also, I sought to know the existence and application of PC policies and availability of PC drugs. For this purpose, the semi-interview questionnaire and interview guide were used to gather adequate data. With regard to data saturation, in the course of the interview, I discovered there was no any new information coming out from the different categories of participants. Generally, they were saying the same things regarding major questions and key focus areas. Also, it reached a point where there was no new issues emerging that would led to seeking more sample or generating new questions. The core objectives of the research were duly covered in the responses from the different healthcare workers who participated. In addition, Fusch and Ness (2015) stressed, I am satisfied that data saturation was reached because there is enough information to replicate the study.

3.10 Data collection process

Data collection was conducted by the researcher for a period of one month from 20th August until 20th September 2019. Semi-structured, in-depth one-on-one, face-to-face interviews were used to collect data. Before the interview started, the researcher ensured that distractions were prevented by switching off phones and asking the interviewee to place a “Do not disturb sign – interview in process” sign on the door. The researcher had prepared the sign beforehand and brought it along.

Prior to the start of each interview, an informed consent form (Appendix B) was provided, reminding the participant of the research project’s aim. The researcher allowed time to answer any

questions or clarify anything that may have been unclear. In accordance with ethical principles, participants were informed that refusal to take part would not compromise their position in their workplace or their professional status. Participants were assured anonymity and confidentiality and the researcher made it clear to the participant that his/her participation was voluntary and that s/he may withdraw his/her participation at any time. This meant that any presentations of their views, including published reports, would be anonymous. Once participants were happy with the information provided and had the opportunity to ask questions, consent forms were signed by both the participant and the researcher.

Use of questions during the interviews enabled the researcher to explore, refine, summarise and clarify understanding and also to ensure that information provided by participants was perceived correctly.

The interviews were conducted in an environment familiar to the participants and at a time convenient to them. The researcher conducted all the interviews in English which is the main language of communication in the hospitals. The verbal content of the interviews was recorded using Digital recorder and notes were taken and these were available as part of the raw data.

3.11 Data analysis

A thematic framework was used to inform the systematic approach to data analysis. The researcher used thematic analysis because the study was qualitative and descriptive in nature.¹⁰⁰ The researcher had to be clear about what was expressly said by the participants and what was observed and documented by the researcher during the interviews. The researcher transcribed recorded interview sessions verbatim. In addition, an independent person checked the transcribed data to verify whether transcriptions were a true interpretation of the interviews. Then, using hard copies of the transcribed interviews, the researcher tried to immerse himself into the data by reading and re-reading the transcripts to familiarise and gain critical understanding of the data.¹⁰¹ Data was then coded into meaningful and manageable briefs through the use of quotations, passages and single words. The researcher started noting and extracting notable points, phrases/sentences with similar or related meanings which were then written in a separate sheet of paper. The researcher ensured that data was read repeatedly to ensure no point was missed. The researcher then allocated codes to identify themes and sub-themes and to determine whether there were coherent patterns

emerging. After coherent patterns were identified, the researcher moved on to the next level of analysis which provided rich data that informed the findings of this study.

Data that did not have any specific code which is referred to as deviant theme was not discarded, rather it was allocated and kept in a new code.¹⁰⁰

At this stage, an independent researcher who had no prior knowledge about the study was invited to check through the coding and thematic analysis that emerged from the data analysis. All qualitative analysis, coding and thematic allocation was done manually without the aid of a computer-assisted software. At the end of data analysis, the researcher developed a table of the findings as shown in Table 3.

3.12 The strategy used to achieve Rigor and Trustworthiness of the study

In qualitative studies, it is critical to ensure that methods and instruments used to collect data are credible, transferable, dependable and confirmable for the findings to be meaningful and useful.¹⁰² Thus, for the verification of the accuracy of instruments and findings in this study, the following criteria was adhered to. The first criteria, Credibility asks the question: “is this true?” This mirrors an attempt to stay true to the raised reality expressed by the participants, rather than the interpretation of views expressed from the interviewer’s own outlining of reality.^{98, 103} In order to ensure the credibility of the study, the researcher conducted Face-face data collection, took field notes and invited an independent researcher who checked and verified the transcriptions and analyzed data. The second criteria is transferability which refers to the degree to which the findings of this research could be useful or relevant in other contexts.⁹⁹ It was then important to keep in mind that an individual’s perception or views cannot be generalized to the entire population. Methods employed in the study have been explicitly documented which would allow another researcher to make inferences as to whether the study could be transferable in their context. The third criteria, Dependability implies the extent to which the findings are repeatable,¹⁰⁰ stable and confirmable to the interpretation of data.¹⁰¹ In this study, the researcher explained clearly how participants were recruited, data collected, analyzed and interpreted in a manner that would allow an independent person to review and examine the study process and data analysis in order to ensure that the findings are consistent and could be repeated.

The last criteria, Reflexivity requires that one is aware of one's own interests, specifically within the context of power relations.¹⁰⁴ The researcher considered potential bias since the researcher had worked in one of the sites. To minimise potential bias, the researcher had to bracket his preconceived ideas. Bracketing in qualitative studies is used to alleviate the potentially toxic effect of preconceptions that may stain the research process.¹⁰¹ Therefore, the researcher tried to remain self-aware and objective in the interviewing process by ensuring that the questions in the interview schedule were not leading, were the same for all participants and that interviewing skills comprised of an objective process whereby each participant felt free enough to voice his/her own views.

3.13 Data storage and confidentiality

To ensure confidentiality and anonymity of collected data, study identity numbers were used for participants instead of their real names so that there would be no way of linking information from the interviews to the participants. Data stored as hard copies, for instance transcripts and field notes were kept in a locked cabinet which only the researcher had access to. Password protection for security was applied to all electronic materials stored on the researcher's laptop and back up on a hard drive was ensured. This data will be retained for a minimum period of ten years as stipulated in the Medical Research Council Guidelines.¹⁰⁵

3.14 Ethical consideration

Before the researcher commenced data collection, ethical approval was received from the University of Cape Town Health Research Ethics Committee (UCT HREC) and Lesotho's National Health Research Ethics Committee also known as Institutional Review Board (IRB). The researcher further sought permission to conduct the study from all three hospitals. There were no incidences of distress experience by participants during the interviews. The researcher respected the autonomy of the participants and all ethical principles were observed including, informed consent, privacy, confidentiality and anonymity as well as voluntary participation.¹⁰⁶ The researcher ensured that adequate information was given with respect to the use of Digital recorder and the dissemination of the research findings in a report so that the participants understood thoroughly before giving their consent and participating voluntarily. Also, participants were given an opportunity to ask questions about the intended study.

Confidentiality and anonymity were further ensured by maintaining that there was no way of linking information from the interviews to the participants as identity numbers were used in all written and transcribed data. Informed consent was sought from all participants before interviews started and all participants consented by signing the consent forms presented to them by the researcher without being coerced or pressured. The research-maintained privacy by conducting all interviews on an individual basis in a private space, free from noise or any disturbances.

Autonomy was fostered by giving participants permission to stop the interview at any time if they experienced any distress and their decision to withdrawal would not compromise them or their work in any way.

3.15 Summary and Conclusion

This chapter provided information regarding the qualitative research method and phenomenological approach to the study. It concludes by describing how rigor and trustworthiness of study instruments and findings were achieved and which ethical principles the researcher had to consider and adhere to during the duration of the study until its completion. The next chapter presents the results from this analysis.

CHAPTER 4: PRESENTATION OF RESULTS

4.1 Introduction

This chapter presents results of the research carried out to understand the perceptions and experiences of health care workers regarding the need for palliative care services for patients and families facing a diagnosis of a life-threatening conditions, in Lesotho. The findings were generated from analyzed data which was collected from the semi-structured interviews conducted with 12 health care workers employed in three (3) selected hospitals in Lesotho. All the interviews were scheduled during working hours. In Queen Mamohato Memorial Hospital and Saint James Mission Hospital, there was a total of 9 attendees each comprising of 4 nurses, 2 doctors, 2 pharmacists and 1 social worker. At the Centre for Equal Health Access Lesotho (CEHAL) Hospital, a total of 12 eligible participants attended and were made up of 5 nurses, 3 doctors, 2 pharmacists and 2 social workers.

4.2 Sample demographics

A total of three doctors, three pharmacists, three social worker and three nurses participated in the semi-structured interviews. Eight of them were female and 4 were male. In each of the selected hospitals, a doctor (manager/doctor), pharmacist, nurse and social worker, were interviewed to have a balance of information at both operational and management levels. The three doctors were in management positions, but only one has ongoing part time training in palliative care, the rest of the participants claimed to have some level of exposure to palliative care. For confidentiality, each participant is identified with participant and hospital study identity as follows C001, C002, C003, C004, Q001, Q002, Q003, Q004, S001, S002, S003 and S004.

Table 2: Summary of participants' recruitment process

HOSPITAL	DOCTOR	NURSES	PHARMACISTS	SOCIAL WORKERS	TOTAL
Attendance during the clinical meeting					
Queen Mamohato Memorial Hospital	2	4	2	1	9
Saint James Mission Hospital	2	4	2	1	9
Centre for Equal Health Access Lesotho (CEHAL) Hospital	3	5	2	2	12
Participants with voluntary consent					
Queen Mamohato Memorial Hospital	2	3	1	1	7
Saint James Mission Hospital	1	4	1	1	7
Centre for Equal Health Access Lesotho (CEHAL) Hospital	1	4	1	2	8
Participants who made it to the interview					
Queen Mamohato Memorial Hospital	2	3	1	1	7
Saint James Mission Hospital					
Centre for Equal Health Access Lesotho (CEHAL) Hospital	1	1	1	1	4

Table 3: Themes and sub-themes

Theme 1	Theme 2	Theme 3	Theme 4
Burden of disease	Burden of care	Infrastructure and resources for PC	Patient related aspects of PC
1.1 NCDs	2.1 Traditional focus on pathology	3.1 Lack of PC referral facilities and beds	4.1 Denial
1.2 Infectious diseases/ Stage 3-4 HIV	2.2 Psychosocial support	3.2 Referral criteria for palliative care services	4.2 Late presentation
1.3 Loss of dignity	2.3 Lack of empathy	3.3 Access to PC meds	4.3 Cultural factors
1.4 Chronic pain		3.4 Policies and procedures	
1.5 End stage cancer		3.5 Staffing challenges	

Source: Researcher’s compilation 2020

4.3 Themes and sub-themes

The data collected was analysed, coded and grouped into five (5) categories from which different themes and sub-themes emerged. Deviant themes were also compared and contrasted with the rest of the themes that emerged. In this study, deviant themes initially identified were later merged with existing themes.

The themes are presented in a table format above (Table 3) and discussed in subsequent sections. The five categories include Burden of Disease, Burden of Care, Challenges and opportunities, Patient related aspects in palliative care and Identification of patients for palliative care.

4.3.1 Theme 1: Burden of Disease

Most participants indicated different health conditions with cumulative burden of diseases requiring the need for palliative care for many patients.

4.3.1.1 Non-Communicable Diseases- NCDs

Most participants agreed that chronic diseases with high mortality rates are the prevalent palliative care conditions in their respective hospitals. The theme is further explored under the following four sub-themes.

Some participants classified prevalent palliative care conditions under metabolic diseases with highest mortality as indicated in the statements below:

“ PC is applicable to infectious diseases as well as the metabolic diseases like diabetes... also hypertension cases...And obviously, renal failure patients that are newly diagnosed diabetic...” S001

“There are those patients with complicated conditions or cancer, those are the type of patients who need palliative care, and.... patients with the complicated chronic conditions; like TB, chronic TB, like the (MDR- TB...,”) C001.

4.3.1.2 Loss of dignity

One participant observed that patients with poor quality of life also demonstrated sense of hopelessness as a result of burden of chronic disease.

“...With paraplegic (the paraplegics), we can also include the stroke people (patients). I think everybody else who feels helpless (hopeless), who cannot do anything for themselves because any of their organs, any of their everyday life has changed.” Q004

4.3.1.3. Infectious diseases especially Stage 3-4 HIV/AIDS

Some of the participants' pointed out that high incidences infectious diseases such as HIV/AIDS are also parts of chronic prevalent conditions that need more than acute care:

“People with Cryptococci meningitis who were thought to be negative. Most of them, were found to be HIV positive...” S001.

“You know we do find people diagnosed with TB here but because we are not treating... and of course there are a lots of cervical cancer patients in gynae wards found to have HIV” CO03

4.3.1.4. Chronic Pain

Some participants highlighted that pain symptom was often a factor that prompts patient to visit the hospital.

“There are patients diagnosed with cancer for at least two years, but because of pain, they are here for us to assist them because they have been already told that with the condition they have, they are not going to be cured... ,” S003

“Even when you see that here, there is really not much we can do, but... just about managing pain, maybe the person is in pain... ”Q003

“Patients with chronic conditions like cancers, heart failure should be having their routine check-ups here.” Q001

4.3.1.5 End-stage cancer

Most of the participants agreed that end-stage cancer patients usually qualify for terminal/palliative care services. Generally, their positions are captured in the statements below;

“A patient with cancer especially patients who are in their last stage or terminal stages, they will qualify for palliative care...Q002

“...mostly cancer patients and of course HIV patients presented late; they are in pain. But mostly, I have seen a number of cancer patients here.”S003

4.3.2 Theme 2: Burden of Care

4.3.2.1. Traditional focus on pathology

Many participants focused solely on, and gave priority to, patients’ pathology over other forms of supportive care services in their hospitals.

“...we don’t really go too much into details on that, so we don’t spend time trying to dig into the psychological aspect of the illness. We mostly concentrate on the pathology, Q001”

“...there is no clinical psychologist to take care of their psychological problems which they are passing through,” Q003.

“...we don’t really go into too much details on that. You know our patient turnover is quite high especially in the internal medicine ward,” S001.

4.3.2.2 Psychosocial support

Many participants enunciated different psychosocial support practiced in their respective hospital units.

“.....it's not easy because, uh, you don't have much time to sit down with the patients, to make them understand their conditions...”Q002

One participant affirmed that due to high patients' turnovers, they don't have enough time to offer personalized services to patients beyond medical treatments.

“...psycho-social aspects as for us, to be honest in the clinical setting, we don't really go into too much details on that. You know our turnover is quite high especially in the internal medicine ward,” S001.

4.3.2.3 HCWs Lack of Empathy

Many participants expressed lack of empathy in their treatment of patients by turning them down for admission and discrimination practices of selecting particular type of patients and health conditions they give attention to.

“We have been neglecting our patients. When they come, we say, this is just... home-based care. This is just, okay, this is the family problem...it is not our problem” C002.

“...you do whatever routine you have. Then as a person you don't have much time to sit down with the patients, to make them understand their conditions, to make them feel that you know, and be able to feel the love of people who are around them,” Q002.

“Yeah. So that kind of patient, even when they present at the health facility outreach like PHC department, the focus is more on those kinds of patients that are not really bad eh, So, it is like we leave our patients on their own...” C003

4.3.3 Infrastructure and resources for PC

4.3.3.1. Lack of PC referral facilities and beds

A participant acknowledged that patients needed help, but nowhere to get such help.

“We don't have much to do. We don't have anywhere to send (refer) them to for renal dialysis or for organ donation of whatever organ that could help them.” S004.

A participant noted there were instances when patients were sent back home because of inadequate bed spaces.

“..So, with patients who have (suffering from) chronic conditions then the patient will (would) be sent home for (home based palliative care) palliative care, because we cannot keep anybody here for much longer than it's necessary for the hospital,”S004

4.3.3.2 Referral criteria for palliative care services

Participants indicated lack of standard referral criteria to other health facilities and home-based care is often implemented casually.

“So, it is better that people understand that they are still our patients. They still need our support. Even when we discharge them home, we still need to see them,”C001

“But I think it's better maybe we have a kind of workshop where community, health workers can understand this scenario because, people think that it is ONLY at the hospital where they can get help”C001

“Mostly, we have had a lot of cancer patients because we find them in government hospitals, they are always told to just go home...,” Q003

In particular, one participant raised concern about discharging the terminally-ill patients into the community without a program to support them;

Not really like a program and you know..., here we are much interested in HIV, TB and other stuff. ...Yeah..... So it is like, we leave our patients to be on their own.”S001

Most participants expressed that they were unable to cope with too many patients who needed different kinds of care as a result of burden of diseases.

“I feel they are not getting enough attention because they will be mixed with the normal patients who don't need palliative care.... That they would have to be fed, we feel like they are bothering us and now, they are too much (many).” Q003.

“...Then as a person is not, uh, you don't have much time to sit down with the patients, make them understand their condition, make them feel, you know, feel the love of people that are around them,” C003.

“If we say home-based care, it should be home based care. We shouldn't find us readmitting that patient again because they have exacerbation of COPD....”C001

“...we don't really go into too much details on that. You know our turnover is quite high especially in the internal medicine ward,” S001.

4.3.3.3 Access to PC medications

Some participants indicated that their hospitals have access to different schedules of pain-relieving medication, but they are expensive.

“...most government hospitals have in stocks pain medications like NSAIDS, and stronger schedule and strictly schedule medications – pethidine...” Q003

“Of course, they are not easily accessible even in the hospitals we restrict them. They are expensive compared to other medication,”Q002.

“..... We find sometimes financially they have a problem. And then, this is a long-term treatment is not like in five days the patient is going to be okay. The drug is expensive; the patient doesn't have money,” COO3

Participants explained different medication accessibility control systems in hospitals.

“Any schedule five, six, seven, we have different cupboards where we keep, uh, those kinds of pain management medications or medication. ... and you are not supposed to give that kind of pain medications without a prescription,” C002.

“....We control them. We keep them in the locked cupboard.....the book must be signed, so another staff will come to cross-check,” S002.

4.3.3.3.1 Lack of pain medication guidelines or protocol

All participants tasked with pain medication management explained protocol for administering medication in their respective hospitals.

“..... we usually go through teaching people (the staff the WHO) analgesic ladder. You don't need to rush into giving patient pethidine.... Maybe sometimes, we give them NSAID and adjuvants. And then when the problem gets worse, we give stronger opioids,” S002.

“I don't know the medication themselves, but I know there is pain management protocol that is followed for every patient. The nurse will come and monitor the patient and ask how severe the pain is and gives pain medications according to the level of pain,” S004

4.3.3.3.2 Inadequate stock of pain medications in government and public health Institutions

Participants revealed that there is shortage of certain pain medications especially in public health facilities.

“But then when it comes to pethidine or morphine especially, I think it is okay that we don't have it readily available for us to prescribe because you need people with experience in using these medications before they can be prescribed.” Q003

“We don't have morphine. We use Pethidine injection if they are admitted,” S003.

“But if maybe we don't have something or we didn't have such medication, we used to call other hospitals to borrow us. It is what we are doing here. But if they don't have, we just advise them to go and buy,” C003.

4.3.3.4 Policies and procedures

All participants indicated that they are not aware of any policy or structured program guidelines for palliative care in their hospitals and Lesotho.

4.3.3.4.1 Absence of PC guidelines in health facilities

Most participants responded that there were no existing guidelines or protocol for palliative care.

“No, I think we have....will check with COHSASA if there is any regarding to that. We don't have a clear guideline... up to this point, we don't have any clear palliative care protocol in the country,” Q001

“...I don't remember because normally we have different doctors here. But there are people with palliative care needs, we normally refer them to the doctors.” C003

“I am not aware of any. I don't think we have. ...I can't remember seeing anything to do with palliative care in the policy that we have.” Q003

4.3.3.4.2 Need to develop National PC guidelines and policy for the country

Some participants acknowledged the need for country-specific protocol and guidelines on palliative care.

“Although, we can have a protocol from the WHO, we still may need to have a protocol from the country itself, from the ministry, and then we are waiting for those ones,” S001.

“.....think it will really be good to have something like that, to say this is the checklist,” C001.

“There should be structure that is clear as if it is palliative care and there are things that bother you; where should the patient go? Q001

4.3.3.5 Staffing challenges

Participants recognized the need for extra support for patients, but resources like staff were too little in numbers or non-existent in their respective hospitals.

4.3.3.5.1 Inadequate manpower especially the psychosocial health workers

Many participants revealed that there were none or insufficient numbers of health care professionals to provide psycho-social support in their respective hospitals.

“There is more need for support either religious or social or any other needed support, because when you have been told that you have a certain chronic disease condition; like most of our patients in medical ward,” Q003. “If we can find someone, maybe like a pastor to come and visit us more often, because these people they need even spiritual care support...” S003

“We have counsellors here in the hospital, but there are no clinical psychologists to manage their psychological problems which they may be going through,” C001

4.3.3.5.2 Education and Training of Health Care Workers

Participants agreed that level of palliative care awareness and knowledge is low.

“...most staff have never benefitted from any palliative care training courses...”Q003

“...we all missed this training in school and we need to attend seminars and workshops to acquire the concepts” C003.

Also, participants agreed that training opportunity is needed in the areas of education and training of HCWs especially for the community-based health workers.

“If, for example, we say for us as a hospital, we are to educate everyone here about palliative care activities, if possible, we need many, many people to come together and agree; this is the situation and how should we handle it,” Q003

“The community health care workers are more equipped..... They need more training and they should get paid....,”S004.

So, I think we need this because there's no kind of training, workshop for nurses and doctors in that regard. So, we can learn a lot when we have opportunities to learn about it,” C001.

4.3.4. Patient related aspects in palliative care

4.3.4.1 Denial

Participants observed attitude of denial or rejection of the reality of health conditions among patients.

“Sometimes, I think our patients who are ill with terminal diseases who need palliative care do not get the services, they die of severe pains, anxiety and depression before their time,”C001.

“I think the level of understanding of and the meaning of palliative care itself is very low. People actually don't understand what it means,”C001

“So, you find that some would accept but for some it's very difficult. Even if they are in pain, you find the doctor says you are sick. They just refuse that they are sick.” Q002.

4.3.4.2 Late presentation

Also, some participants mentioned situations where patients reject or deny their confirmed diagnosed medical conditions, and patients deliberately delay seeking medical help.

“Some of them delay, move from one hospital to the other.... And of course, most of the patients come really when it is late. They are usually at terminal stage,”C001.

...Most people come to hospital with the expectation to get fine. They have HIV/AIDS or cancer; even when they are at their last hours, they want people who will be saying I am giving you this medication. You are going to be fine,” S004.

4.3.4.3 Cultural factors

Participants expressed that some African cultural practices regarding health affect knowledge and attitudes towards palliative care.

“Health seeking behaviours as Africans is poor and the number of people with cancer is often higher and our people are usually afraid of any impending death,” S003.

“...But with our people, they don't feel comfortable staying with the patient at that moment, ... because the family members are not ready to witness someone dying in the house or someone is experiencing terminal sufferings,” C004

“If you relate it to our African beliefs, I think people don't want to hear about terminal illness,” S001

4.4 Summary

The chapter covers the presentation of the study findings under five categories from which themes and sub-themes are derived. The themes are illustrated with the statements from research participants. Main themes included prevalent palliative care conditions, psycho-social support, criteria for palliative care patients' referrals and lack of resources to support PC patients. Other themes that emerged are access to pain medications, understanding palliative care, need for palliative care policies and procedures. Across all the issues raised under each theme, analysis indicates that majority of the participants are in agreement. The next chapter presents a detailed discussion of the findings.

CHAPTER 5: DISCUSSION

5.1 Introduction

This chapter presents a discussion on the crucial aspects of the study findings. Although the research specifically focused on the HCWs perception regarding the need for PC development in Lesotho hospitals, many other important issues came up such as PC practices, home based care. Other salient issues include challenges to PC integration and related policies that support PC development as described by WHO PHS which advocates availability of essential medication, education and training in PC, and effective implementation of PC at all levels of care.

The study findings have highlighted and confirmed the dire needs for provision of PC services in Lesotho, an indication of dearth of PC services in most of the clinical practices coupled with burden of diseases on patients with life-threatening diseases. There was an overwhelming expression of gap in the service provisions in Lesotho as expressed by the participants in this research. In the subsequent sections, the researcher presents discussion on key findings; (their palliative-care) perceptions, integration of PC into health care systems, practices of Palliative Care (current palliative care practice scenarios in Lesotho), PC medications, Policies issues in PC, education and training in PC as well as challenges to PC development and implementation.

5.2 Perceptions of Palliative Care among Health Care Workers (HCWs)

The study primarily sought to examine perceptions of health care workers regarding the need for palliative care services in three selected hospitals in Lesotho. Therefore, one of the study objectives **was** to identify health care workers knowledge, attitudes and beliefs on palliative care given the rationale that these play important roles in PC integration and quality of delivery. To this end, the study finding reveals that, although HCWs have adequate knowledge and experience of diseases and their burdens, their knowledge and practices of PC are varied and limited. This agrees with earlier study in the USA by Aldridge et al. 2016 who found that majority of HCWs studied had limited knowledge and practices in PC services.¹⁰⁷ Other studies have also noted similar results¹⁰⁸ In addition, the study finding indicates that understanding of the different kinds of health conditions that qualify for PC among HCWs differs from hospital to hospital and across categories of HCWs. Healthcare workers who work in medical ward demonstrate appreciable understanding of PC compared to those who provides support and psycho-social services.

Further, the study findings reveal misconception of PC by HCWs as expressed in the strong association of the concept of “helplessness” with palliative care. The findings indicate that HCWs understand helplessness as one of major conditions that qualifies for PC. There was particular reference to paraplegic people and generally those who are weak and cannot help themselves as examples of helplessness. This understanding is a feedback on the healthcare workers’ limited understanding of PC as well as the need for it. Hence, HCWs or institution with this kind of understanding may be caught in the web of prioritising access for paraplegic patients over those who may need PC more urgently. Also, the association made with palliative care and helplessness has resulted in inability to appreciate the benefits of PC to a point of HCWs, patients and families disapproving the use of the term ‘palliative care’.

Similarly, Aldridge et al.’s study regarding PC practice in some US hospitals finds similar result regarding the concept helplessness in PC services. The study which included 140 medical oncologists and mid-level providers found the use of the words “palliative care” as disturbing because it invoked sense of hopelessness in patients and families as compared to the use of “supportive care.” As such, these health professionals preferred the term “supportive care.”⁶⁸ Some of the studies²³ reviewed by the researchers indicate perception problems which are associated with the use and meaning of professional terminologies of “palliative care” and “hospice.” This is an indication that medical/clinical terminology and its understanding affect HCWs’ perception of PC as well as its acceptance. Other PC misconceptions identified is a situation where HCWs consider PC as mainly a symptom management program for patients with life-limiting condition. Hence, this leads to some HCWs assuming that palliative care is necessary only after ‘disease modifying treatment’ had been exhausted.⁷⁷

Overall, in relation to the study rationale stated above, this study concludes that the misconceptions or inadequate knowledge of PC impacts on access to, and quality of PC services delivered to patients as well as integration and development of PC into national health systems in Lesotho. Further, the study finding reveals that HCWs’ limited PC knowledge interplays with their attitudes and beliefs towards patient’s treatment and care.

For instance, some participants based their interventions and treatment of patients on assumptions rather than professional and quality clinical assessment.

As some of the participants indicated, they relied on assumption as last resort because there were no clear guidelines for the professionals to follow. Again, the rationale of the study surfaces as it is evident that HCWs' perception impacts the quality of PC currently practised in the hospitals. This also indicates that patients are left in the care of HWCs who do not understand PC dynamics in patients' health care needs. Hence, as Steinman and Auerbach, 2016, indicate there is a need for "a paradigm shift that better defines the role of the in-patient physician in chronic diseases management."¹⁰⁹

This study therefore has confirmed the misconceptions or inadequate knowledge of PC impacts on access to, and quality of PC services delivered to patients as well as the urgent needs for the development and integration of PC into national health systems in Lesotho. The next section insight into how HCWs' interrelationship of burdens of care and diseases as well as home-based care.

5.3 Burdens of Care and Diseases, and Home-based Care

HCWs' burden of care is a critical issue identified in the study. HCWs are affected by what has been described as HCWs' stressful but rewarding experience of PC⁸¹ resulting from high turnover of patients and burden of chronic disease on patients requiring treatment. A number of HCWs expressed that working with high number of palliative patients in poorly resourced and high-risk environment was challenging for them.¹¹⁰ Similar studies¹¹¹ identified burnouts or fatigue among as common occurrence among HCWs especially in cases of palliative care. In this regard, PC was seen as high burden of care for the HCWs⁸¹ which may impact their efficiency in delivery of quality PC services. For instance, the study finding suggests that initiation [of] or resorting to home-based care by HCWs may be a sign of being fed up as a result of burden of care and patients' burden of disease rather being a continuation of patients' treatment whose situations can no longer be managed at the hospitals. Some participants considered the home-based care option as an indirect way of sending patients home to die as they conclude "that nothing more could be done" for the chronically ill-patients. As such, hospitals may decline bed admission when patients no longer need, in-hospital-based services such as injections or oxygen (for those on life support).¹¹²

In many instances, participants admitted that patients were often discharged to home-based care without standard home-based care process and procedures.¹¹³ In this regard, the study findings did

not provide any indication of details of home-based care in terms of transition and continuity of care.

While burden of care and diseases, poverty or financial hardship may play a key role in HCWs' decision in initiating home-based care.⁸² The study further establishes that, hospitals have challenges in terms of patients-bed ratio or space capacity to the number of patients and of course the patients comfort and this may offer an opportunity to have a dignified home care as good options. Therefore, home-based care is considered as an alternative that may relieve burdens on hospitals infrastructure and resources as well as burden of care on HCWs.

5.4 Integration of PC into health care systems

One of the objectives of the study is to identify the need for PC provision. The objective links to the integration of PC into national health care systems in Lesotho. However, the finding of the study indicates that most participants' understanding of PC integration differs as indicated in other studies^{68, 114} reviewed. While some participants expressed that PC must be every HCW's business, others viewed PC integration as having specific department and separate human resources.⁶⁸ There was also an understanding that PC integration is sharing of infrastructure, funding, donations, and human resource as well as patients being kept in one unit separate from other patients because of their unique health conditions. However, scholars such as Steinman and Mc Cornick, 2016, explain that integrated PC is putting together all clinical and administrative service in order to provide continuity of care between all players involved in the care of patients receiving PC.^{100, 103} Also, other studies support the study finding that it is essential to integrate PC services, even though not all participants had the same views of integration of PC being as vital as the evidence shows^{109, 115}

A significant finding of this research is that PC is not well developed or integrated at local or national levels of health care in Lesotho. Hence, integration of PC services into Lesotho main health care delivery system is a necessity given the importance of PC in every health care systems as well as the growing number of patients requiring advanced level of care in the country. However, it has been observed that PC integration in countries such as Lesotho has been slow and ineffective because of certain challenges. These challenges are discussed in the next section.

5.5 Challenges to PC integration and implementation

Given the above discussion on PC integration, it is clear that there are diverse challenges and specific barriers to quality PC integration in health care systems in Lesotho.

The study findings support the existence of challenges earlier identified in the literature reviewed. Some of the challenges identified include lack of PC education, staffing needs and knowledge gap in the healthcare sector, inadequate advocacy for PC integration,⁷⁰ impacts of cultural beliefs and inadequate financing of PC services as well as PC drugs administration.

5.5.1 PC drug availability

A major finding of the study is the issue of accessibility to, and affordability of essential PC medications and how these two variables affect PC integration and implementation. Most participants acknowledged that some medications were available, but government policy limited patient's access to them. Also, drugs prescribers and those responsible for administering the medications are also limited, in terms of authority to prescribe and administer some medications. For instance, prescriptions of medication are only limited to qualified doctors. Some participants, such as nurses, responded that they were not permitted to prescribe medication particularly opioids. Also, it was indicated that nurses did not have adequate training in prescribing pain control medication such as opioids. The WHA (67.19) recommendation mandated adequate supply of important PC medicines and administration.⁵⁴ Also, the Lancet Commission on Global Access to Palliative Care and Pain Relief, 2018 recommends, that medication must be available at all times if PC services are to be enhanced in health institutions worldwide.¹¹⁶ Yet, availability of medications is linked to the WHO Public Health Strategy (PHS) recommendation which requires that prescribers must be trained in PC and must allow not only doctors but also clinical officers and nurses to prescribe and administer drugs. In this regard, Jagwe⁷¹ indicates that PHS recommendation may not be achieved if these gaps are not covered or corrected.

In addition, while findings indicate that there was availability of different schedules of pain-relieving medication in most of the hospitals, most of them do not conform to the WHO PC medication list.⁶⁵ For instance, the study finding indicates that pethidine is usually more available and utilized than morphine. However, the result of study conducted by Jacob, 2017, discouraged the use of pethidine in chronic pain management.¹⁰⁸ Similarly, the British Medical Journal reports

that morphine is said to be the most appropriate drug for moderate to severe pain relief. Yet, the study finds that access to this medication remains very poor in Lesotho, even though literature reviewed suggests that morphine is inexpensive, safe and effective.^{67, 116} The Lancet Commission report 2018 offers some insight regarding the situation. The report indicates that only 0·1 metric tonnes of morphine-equivalent opioids are distributed to low-income countries out of the 298·5 million metric tonnes distributed in the world each year. Of this, world's poor countries only get 1% of the morphine distributed worldwide which is not enough to meet the palliative care pain control needs of patients suffering pains from chronic and life-limiting conditions.¹¹⁷

In addition, this study agrees with Saini, 2016, that major constraints to increased usage of pain management medication among others are weak supply chain management, absence of robust and formal policies and regulations that support the availability and accessibility of pain control medications particularly the opioids.¹¹⁶ Also, and as similar studies indicate, where government policies are in place, its strict application disrupts availability and access to opioids medications in many countries in sub-Saharan Africa including Lesotho.^{9, 67, 116, 118}

Further, the study finds that lack of, or limited access to medications is linked to high cost of medication particularly when patients have to purchase them in pharmacies outside the hospital facility. Participants noted there are cases where certain medications are not available in hospitals and even when available patients are expected to pay for them. Yet, many of the patients in public hospitals are poor and so cannot afford to pay for hospital services and expensive medications. This problem with this situation is that it has serious impact on achievement of Universal Health Coverage in Lesotho based on the findings which confirm that some PC medication like morphine has to be bought personally by the patients because of lack of access to these medication in State-owned hospitals. It is also an indication that PC is costly for both hospitals and patients. The findings suggest that the reason for this is likely due to lack of integration and lack of review of the essential Medicines List.

On the contrary, other studies, such as Weissman and Meier 2008, argue that 'having PC services in the hospital setting can reduce costs.'¹¹⁹ However, the study has shown that this is not the case in Lesotho. Yet, the Lancet Commission on Global Access to Palliative Care and Pain Relief, 2018, has indicated possibility of reduction of PC services costs in hospitals through the design of an

essential package of palliative care medicines, basic equipment, and human resources for low-income countries such as Lesotho.¹¹⁷

Furthermore, the study finds a relationship between access to medication especially pain control ones like opioid and the fundamental human right component of PC. As the United Nations (UN) maintains, failure to ensure access to controlled medicines for the relief of pain and suffering threatens the fundamental human right to health and to protection against cruel, inhuman and or degrading treatment.^{29, 57} In this regard, the study highlights the importance of the WHO directive that, it is a fundamental human right of patients with severe pain to have access to pain-alleviating medicines.³ This position is further underscored by the Lancet Commission on Palliative Care and Pain Relief report 2018 which considers the inequity in addressing pain alleviation globally as “a heinous injustice that has been largely ignored in global health.”¹¹⁷ Therefore, for a country to claim it has made significant progress towards PC services, essential medications, especially the opioids must be easily accessible and affordable at all levels of care. The study could not establish such achievement at any level of healthcare system in Lesotho.

The next section provides insight into cultural beliefs and practices and some of its impacts on PC and drugs administration such as combination of traditional medication with orthodox medication.

5.5.2 Impacts of Cultural beliefs and practices in PC

O'Brien 2011 observed that patients as well as HCWs are themselves products of different cultural milieu that wields strong influence on their attitudes and behaviours.⁷⁸ This study finds that there is a low level of understanding and willingness to accept the reality of terminal illnesses diagnosis by many patients and their families in Lesotho. As the study participants revealed, this can be attributed to certain African health practices and religious beliefs. For instance, many patients believe that miraculous recovery from terminal disease (such as cancer) is possible.^{120, 121} The study finds that such beliefs lead to denial of diagnosis and delay of treatment among patients. This is also partly the reason for commonly observed defaults in patient's decision to embrace PC services wholly and timely.

In addition, the study reveals patients' habit of simultaneous combination of traditional medication with recommended orthodox medication.¹²² Study participants indicated that patients often refuse to comply with the hospitals scheduled follow-up visit appointments while some of them seek

alternative help with traditional healers. Also, there is slight indication that the same cultural beliefs affect HCWs in terms of their responses and attitudes towards patients.

Harding et al argued that some of these cultural behaviours are perpetuated by the exclusion of PC training in most of the training institutions for HCWs which in turn can influence and educate the patients and their families with adequate knowledge of PC.²⁶ Researchers suggest that these cultural beliefs or influences may be positively addressed or modified not to pose a challenge to PC development and implementation but as an opportunity to educate and improve HCWs understanding and decisions regarding pain management and caring for the dying.⁴¹

5.5.3 Communication challenges

Patient-health care workers communication is another major challenge identified in this study. Some studies¹¹⁸ have identified communication challenges as some of the issues in PC development and implementation in cases where HCWs efficiency is hampered by difficulty in communicating poor prognosis and pain management.¹²³ A major communication challenge discovered in this study was ineffective prognosis discussion and communication by the HCWs to patients. Yet, Lazarus' study concluded this could be an issue of staff needs - a problem of lack of team work of (doctors and social workers) that are genuinely trained in effective clinical communication and can cover up for other colleagues who are lack clinical communication skills.¹²³

In addition, family resistance regarding sharing information (which is not as simple as only about communication, but also as unique family dynamics and sensitive cultural and religious issues) is another communication issue explored in the study. The study finds that there is usually a resistance from family members to disclosing medical diagnosis and other information to patients. This raises the issue of human rights – the “right to know” in the sense that it is ethically right that the patient's right to know is recognized and encouraged.¹¹³ However, this study finds that most times patients are not aware of their clinical conditions and the available treatment options. Hence, patients are not given the opportunity of informed decision about their health. Ganca et al's study considered this as doctors' communication problem –

a lack of needed skills in conveying poor prognosis to patients and families.¹²⁴ Although, social workers who are skilled in communication are part of the health care system, yet they are not integrated to meet communication needs especially in PC services.

5.5. 4 Inadequate Resources

As indicated above, HWCs' communication problems are closely linked to staffing needs in hospitals. The study findings identified inadequate human resources particularly inadequately trained in palliative care specialists as a major challenge in PC integration and implementation in hospitals. For instance, the study finding indicates that spiritual care and psychological support such as clinical psychologists and clergy have not been adequately integrated into the holistic PC approach because of inadequate trained specialists. As the study establishes and is described by Fraser, 2017 the major challenge in PC development is linked to shortage of PC trained HCWs.⁶² In addition, the study conducted by Sommerbakk et al.⁴¹ arrived at similar conclusions about the imperative for PC training of HCWs.

Overall, these challenges are not peculiar to PC, because new initiatives such as PC are perceived as increasing the HWCs' clinical burden and additional training needs to update their knowledge and skills.¹²³ Thus, the need for training and educating HCWs remains key, if the PC services must be appropriately developed and implemented in any given institution. The challenge of education and training of HCWs in relation to PC is discussed in next section.

5.5.5 Education and training in PC

HCWs' education is highlighted as a major challenge to PC development in this study.^{18, 34} The study finding pinpoint lack of and/or inadequate health care worker's education and training in PC as a challenge to PC integration in health care systems in Lesotho. For instance, the study findings show that none of the HCWs who participated in the study had a formal clinical PC education or skills in PC such as a degree or certificate program. However, a few HCWs had little exposure in terms of ad-hoc short training in PC, while others are in the course of getting some forms of introductory education in PC. Consequently, some HCWs experience discomfort with conducting effective end-of-life discussions, and are challenged by limited knowledge and application of existing resources resulting into poor explanation of care options.⁶ This is a far cry from the WHO (2007) PHS recommendation which requires that HCWs must be educated and trained towards PC delivery at all levels of care.¹⁶

Aslakson et al.⁴² explains that lack of PC knowledge and skills of HCWs is a noticeable barrier related to lack or inadequate PC education and training. For instance, HCWs' failure to recognise patients' end-of-life phase and their undue concentration more on curative intervention in most health care services is attributed to lack of PC education and training.¹²⁵ In a study conducted in

the United States, Aslakson et al discover that HCWs consider palliative care as equivalent to end-of-life care.^{68, 126} The researchers conclude that this erroneous believe is a direct result of lack of proper PC education and training.

In this regard, these findings resonate with Rawlinson 2004⁷⁰ that concluded that inadequate education and training pose serious threat to the integration of PC in countries' health care system.⁶⁸ Yet, the importance of PC education has been highlighted by African countries resolution through the 2016 Kampala declaration. The resolution indicates that PC education must be included as an integral component of the ongoing education and training offered to HCWs in accordance with their roles and responsibilities.⁴³ This resolution and other recommendations by WHO, international and regional health bodies point to the question of robust government policies and regulations regarding PC. This issue is covered in the next section.

5.6 Policy Issues in PC

The study findings reveal that there is no standard or official protocol that guides the practice of PC in the selected three health facilities in Lesotho. Also, nationally, the study indicates that there is no existing PC policy or structured program guidelines for PC. Yet, literature suggest that for African countries such as Lesotho to have integrated quality PC in their health care systems, they must develop strong and enabling policies to guide and enhance its implementation.^{9, 118} For instance, what is in place in some of the institutions that indicated existence of protocol is an in-house or ad-hoc protocol based on senior health professional's experience. Also, it was discovered that some protocols in place in a particular hospital are arbitrary and do not conform to any formal standards. It is more like a 'use-as-you-go' kind of policy. In another hospital, the medical doctor serves as the reference point when it comes to PC protocol, but the rest of the HCWs are not aware of what protocol to follow in palliative care.

Linking with this finding is a perception that PC is a reserved privilege of doctors. As a result, other HCWs lack awareness and knowledge about the subject and its practice. Therefore, in the absence of the doctor, PC services cannot take place. Generally, PC practice is guided by assumptions and general medical practice knowledge rather than formal policies and protocols.

Moreover, one of the key aspects of PC is community health a component of which is home-based care. However, the study finds that this important aspect is also affected by poor or lack of formal policies. For instance, there is no clear policy on home-based care and patients' referrals for psychosocial and spiritual support. Yet, WHO PHS recommends policy support as a priority in PC at any level including home-based care.¹²⁶

Lack of PC policies indicates that the quality of PC services is doubtful because current practice and delivery of PC are largely characterized by arbitrariness and inconsistency among HCWs and across health institutions as well as in community health situations. Hence, the reason the Lesotho's PC integration status was categorized under capacity building activity under the World PC MAP.⁹ As it currently stands, development and implementation of appropriate policy remains a key issue that must be addressed in addressing gaps and inconsistencies associated with PC practices in health care systems at all levels in Lesotho.^{16, 127}

These findings are supported by Rhee and previous research works.¹⁵ For instance, Sommerbakk et al., recognize policy support in PC and confirm the findings of the study that one of barriers to PC integration and implementation is lack of policies that promote PC education and training of HCWs.¹²⁸ In addition, various studies have identified bureaucracy, leadership style and governance culture as the cause of poor or lack of PC policies. For instance, due to budgetary constraints, some governments may not support the idea of having additional trained HCWs to achieve or promote PC integration into the national health care system services.^{15, 89}

As Aldridge et al. suggest, a PC policy is significant to achievement of PC integration.⁶⁸ South Africa's National Policy Framework and Strategy on PC NPFSPC has been found to be a good example in integration and implementation of PC policy. The goal of the SA NPFSPC is to try to achieve the WHA 67.19 resolution¹²⁹ and this guides the integration of PC in all levels of health care delivery.

5.7 Limitations of the Study

The data used in this study was based on responses generated from the HCWs who participated in the semi-structured interviews in three study sites. These are self-generated responses and may have been influenced by the nature of the topic which is related to their perceptions and experiences of the need for PC.

Also, the study was limited to three study sites which are representatives of hospitals and clinics in Lesotho - both private and public health institutions. However, the experiences and perceptions of the HCWs in these three hospitals may not completely capture in its entirety the overall experiences and perceptions of all HCWs in other hospitals in Lesotho. Therefore, there is possibility of slightly different HCWs' perceptions and experiences as far as PC is concerned.

In addition, twelve (12) participants participated in this study which elicited in depth information from the participants but limited the perceptions to these participants drawing into question the generalisability of the data. However, this is a study, in which the participants specifically have to be HCWs who work in health institutions and have capacity or need for PC even if it is not already in practice. Therefore, future studies can focus on conducting a broader study among HCWs across Lesotho, particularly outside of the capital city. A larger number of study sites and research participants may bring up different angles and more issues that are relevant to and build on this study.

5.8 Significance of the Study

The study provides an assessment and understanding of the existing perceptions and practices of PC among selected HCWs in Lesotho; through whose experience and feedbacks, the researcher is able to understand and document present level of integration and development of PC in the country. Although, it is representative, the researcher is of the view that an assessment of the current the existing perceptions and practices of PC can help to improve PC development, implementation and integration in Lesotho when the issues pinpointed are acknowledge and addressed.

Further, the study can assist government especially relevant organisations such as the Ministry of Health, policymakers and other key stakeholders in the health sector to appreciate the current state of things with regards to PC with the view of providing appropriate interventions.

These may include investment in health infrastructures, health care workers PC capacity building through education and training as well as policy development towards effective and quality PC integration and development.

5.9 Conclusion

This chapter has presented discussion on the findings of the study focusing on key areas of perceptions of healthcare workers, practices of palliative care, home based care and, challenges of PC development and integration as well as policies issues surrounding access to and the current practices of palliative care scenarios in Lesotho. The discussion established that there is need for PC services in Lesotho based on the responses of the research participants. While home based care featured prominently in their discussions, it was highlighted that it practices needs to be standardised for it to be effective level as an integral form of PC services in Lesotho.

The discussion also reflected on a number of challenges facing the development of PC including cultural health practices and beliefs, lack of and/or limited human and material resources for PC, costs of treatment, limited access and availability of essential PC medications, shortage of trained manpower and policy limiting opioids prescribers and other pain medications to only doctors, unlike the practice in other African countries.

CHAPTER 6: CONCLUSION AND RECOMMENDATIONS

6.1 Introduction

In an attempt to understand the need for Palliative care, PC development and integration into the national health care system in Lesotho, the aim of this study was to explore the perceptions of health care workers (HCWs) regarding the need for palliative care services for patients and families facing a diagnosis of life-threatening conditions. This chapter takes into cognizance and synchronized the salient findings during this research process to marshal conclusions and proffer salient recommendations that would scale-up PC service delivery in Lesotho. The researcher is satisfied that the research objectives have been met as demonstrated in discussion linking study findings to the objectives. This is presented subsections 6.2 and subsections 6.2.1, 6.2.2, 6.2.3, 6.2.4 and 6.2.5 below:

6.2 Findings in Relation to Study Objectives

6.2.1 Objective one: To explore selected health care workers' views on the burden of disease at the hospitals where they work and in Lesotho.

This objective was met as shown in the feedback on the participants' perceptions of the Lesotho hospitals in terms of their capacities to help patients suffering from life threatening conditions. These patients need to benefit from palliative supportive to control their burden of symptoms and psychological issues as an extra layer upon their routine care. It was obvious that there were challenges related to an upsurge in number of cases and their burden of care with limited bed spaces. Due to the limited PC skills, medication and other resources, the HCWs' attitude is to quickly initiate home based care to relieve their overwhelming burden of care while concentrating more on the curable ones. Although HCWs suggested an integrated psycho-social-medical approach to the management of these patients which is far-fetched, according to study findings palliative care practically non-existent in Lesotho.

6.2.2 Objective two: To identify PC policies and procedures available in the hospitals.

This objective was achieved as the study findings reveal that there is no standard or official protocol that guides the practice of PC in the selected three health facilities in Lesotho. Similarly, there is no existing national PC policy or structured program guidelines for PC. For instance, there is no clear policy on home-based care and patients' referrals for psychosocial and spiritual support. Generally, PC practice is guided by assumptions and general medical practice knowledge rather than formal policies and protocols.

6.2.3 Objective three: To determine which conditions in the HCWs' views qualify a patient to receive PC.

This objective was met as qualified conditions were identified among patients suffering from life-threatening disease conditions such as Cancer, TB, HIV, Heart diseases or Chronic lung disease. It was revealed that such category of patients can benefit greatly from PC services towards improving their quality of life. However, there was a clear knowledge gap particularly on the management of these conditions holistically taking into cognizance of the physical, psychosocial and spiritual issues of the patient and family members.

6.2.4 Objective four: To identify whether in the HCWs' views there is adequate development and provision of PC services in the hospitals where they work.

This objective was achieved as the study findings exposed the challenges that demonstrated inadequate development and provision of PC services. For instance, the study revealed that patients suffering from life-threatening conditions experienced poor symptoms control like pains and inadequate/lack of PC medications for pain control. Another indicative view are knowledge gaps and burden of care on the HCWs which often prompt them to send PC patients for home-based care rather in-hospital care.

6.2.5 Objective five: To identify knowledge, attitudes and beliefs on PC and linking that to the need for palliative care provision for patients diagnosed with life-threatening conditions including their families.

This objective was met as number of issues demonstrating knowledge, attitudes and beliefs on PC were established. First, there was little or no awareness of PC among the HCWs and the study revealed their knowledge gap in assessing the clinical presentations of the patients that require PC.

Second, this study showed that some medical/clinical terminology and its understanding affect HCWs' perception of PC as well as its delivery. Third, it was also established that HCWs are themselves products of different influential cultural milieu with different beliefs and practices about life issues such as pain, death, burial and mourning rites. Hence, their perceptions, of PC in particular, are influenced by their cultural backgrounds. Thus, this study concludes that perception of HCWs can pose as a challenge to PC understanding and decisions regarding pain management and caring for the dying.

Even with substantial knowledge, implementation of PC was lacking in all levels of care due to lack of clear PC guidelines or policies both locally in the hospitals and at the national level. Participants claimed that most hospital staff believe that PC must be initiated and managed only by doctors. There was also a misunderstanding regarding PC drug administration particularly opioids as some HCWs believed that such medication can only be administered by pharmacists and doctors. Therefore, HCWs belief and attitude to PC is to initiate sending patient for Home-Based Care and also encouraging the patient's meet psychologist or a clergy for support

6.3 Conclusion

Although each hospital had a different pattern of views and challenges, the same reasons and issues were raised all of which suggests primarily that PC services were at low levels of operation, mostly unorganized and in many instances non-existent. The next section presents discussion on recommendations proffered to address the challenges identified in this study towards PC development and integration in Lesotho.

6.4 Recommendations

All governments that are part of WHO agreed to the WHA resolution, this together with the recognition that PC is part of the Right to Health, means that the Lesotho government is legally obligated to ensure access to palliative care for people living in Lesotho.

6.4.1 Recommendation One: Education and professional training

This study establishes that lack or inadequate PC [continuing] education is a major challenge among healthcare workers and it is also a challenge to quality PC services delivery. Hence, PC education and training are recommended as it can play important roles in HCW's knowledge of PC services. For instance, Aldridgel et al. recommended that continuous professional education is essential in addressing perception of PC among HCWs as well as overall improvement in palliative care services.⁶⁸ In view of this, it is recommended, based on the study findings and literature reviewed, that entry point education and Continuing Professional Development (CPD) in the PC field be made compulsory for health care workers in different health care institutions in Lesotho. In this regard, there is need for government and stakeholders' investment in PC education for HCWs. To ensure adherence to this recommendation, Lesotho Government through the Ministry of Health can develop PC entry point education and Continuing Professional Development (CPD) indicators for evaluating PC services in the hospitals and in all levels of health care system.

6.4.2 Recommendation Two: Advocacy

Advocacy is one of the key areas that can lead to PC development in a health care facility as stated by Penn in a British Journal of Nursing.¹²⁸ The findings of the current study indicates that patients were sent home for Home-based care without properly addressing the PC needs of the patients. Therefore, recommendation must focus on identifying advocacy in PC at national and local level for instance, at national level politician can be identified who must advocate for integration of PC into main health care system and develop guidelines and tools across disease group and levels of care addressing ethical issues related to the provision of comprehensive PC. At the local levels, hospitals can identify an individual who may advocate for increased access to PC medication particularly opioids for children and adults in need of PC within the hospital and in the community.

6.4.3 Recommendation Three: Multiple approaches and diverse spectrum of strategy

As Namisango et al.⁶⁷ argue that there will always be challenges to PC development and implementation. Therefore, government and stakeholders must be proactive and innovative by exploring multiple approaches to address challenges of high cost, patients' turnover, limited hospitals resources and lack of PC trained HCWs as well as patients' anti-health behaviours. In view of this, the study and other relevant literature reviewed emphasize that public health strategy for PC must factor in equitable provision to cater for different category of patients and chronic diseases.⁸² For instance, it has been suggested that referrals should be an effective collaboration from hospital to hospital not an escape or decongestion strategy for hospitals that are found wanting in PC services,¹³⁰ In view of this, experts have argued in favour of development and deployment of a diverse spectrum of strategy towards effective public health services delivery for African populace.³² Therefore, Lesotho government will benefit largely from the findings and recommendations of the Lancet Commission on Palliative Care and Pain Relief.

Lesotho government through the ministry of health may adopt the PC PH strategy to its health systems as starting point and in order to achieve access to PC. Government needs to foster national policies, programs, resources, and training on PC among HCWs. Lesotho must focus on promoting early delivery of PC which may reduce unnecessary hospital admission and the use of health care services. Also, the government should advocate for holistic approach which should include physicians, nurses, support worker, social worker, paramedics, pharmacists, physiotherapists and other volunteers from the community.

6.4.4 Recommendation Four: Funding for PC

Adequate funding is essential to the development of PC in health care sector. Hence, the need for funding allocation for PC services in national healthcare budgeting and financing. In this regard, Lesotho Government through the ministry of health annual national health budgeting must have specific allocation for the development of PC. Groeneveld et al.'s support the above statement that funding for PC is essential if PC is to be well developed, implemented and integrated in the mainstream health care systems.⁷³ Hence, availability of fund to support this model of care may help to reduce the need for patient hospital admissions.¹²⁶ Thus, Lesotho Government should provide funding to enable HCWs to acquire PC training material, and other resources such human resource to enable quality integration of PC with other health care services.

6.4.5 Recommendation Five: Policies review and development

If PC is to be promoted in any given setting especially in Lesotho, there is need for PC policy development and implementation through better knowledge of how to formulate appropriate local PC policy agenda. This will require bringing together various stakeholders to build the required consensus and formulate the needed policy.⁶¹ Particularly, such initiative of consensus building must take into cognisance more trained PC HCWs who are the end users of such policies.

Also, existing national health care policy, in relation to WHO Public Health Strategy, need to be reviewed, adapted and developed to ensure palliative care is incorporated into national health systems in low-resourced countries such as Lesotho. Therefore, Lesotho government, may have to initiate more proactive actions in national health care systems and strategy towards entrenchment and improvement of PC services at national level, local hospitals, clinics and hospices.

In addition, Lesotho Ministry of health should have policies that supports implementation of PC in the country more specially policies that backs the availability and accessibility of PC medication such as opioid and allowing more HCWs to be trained on how to prescribe and administer these opioids medication. This statement is supported by South African's NPFSPC document which states that policy implementation should facilitate creating equity in access to PC regardless of the cause of life-threatening condition.¹³¹ Also, there is a need to review the existing strict regulations on prescribers and if possible extending it to nurses as it is practised in other countries.¹¹⁹

Also, strengthening of PC policy should be of utmost importance in national health reforms, just as Sommerbakk et al.,¹¹⁹ Spaulding et al.,¹³² and Kalies et al.¹²⁶ recommend specific and tailored policy support towards effective development and implementation of PC in all institutions of health through a holistic approach that combine individuals' experience with knowledge and acceptable training in PC. For development and scaling up palliative care services in Lesotho, there is need to invest on human resources including training and infrastructures across the country. Nevertheless, the formulation of guidelines within the local hospital community and the national palliative care policy cannot be over-emphasized.

6.5 Summary and Conclusion

The aim and objectives of the study are critical and timely because there is no enough information in medical literature regarding PC services in Lesotho. This study examined the perceptions of

health care workers regarding the need for PC services in Lesotho using 12 research participants drawn from 3 selected hospitals. This is against the backdrop that HCWs are agents of change in health care services particularly PC services in the treatment of patients with life threatening conditions. The roles they play are key to making PC a success. Therefore, their capacity, attitudes, knowledge, beliefs and experiences which sum up their personal and professional perception of PC have huge impacts on PC services delivery at local and national level.

Based on in-depth critical search and review of the available literature, there is a lack of understanding as to whether HCWs in Lesotho have adequate PC knowledge or training and whether they are therefore capable of providing effective palliative care services in their varied workplaces. The study has attempted to expand the present scope of understanding within the context of the HCWs' perceptions of PC and the need for it.

Therefore, the study findings have provided valuable information into the perceptions of the sampled HCWs which might be useful to the Lesotho's Ministry of Health towards the development, improvement and integration of PC services into the Lesotho national health systems and all health care institutions across the country.

In addition, based on the findings of the study as revealed in the perception and experiences of HCWs towards PC and patients, it has shown that PC is essential approach to public health in Lesotho as well as the rest of Africa. More than ever before, PC services are seriously required and needed to be expanded in order to provide easy and consistent access for more patients facing life threatening conditions including their families, to fully enjoy its benefits.

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Appendix A: Approval letter from the University of Cape Town.

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee



Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: sumayah.ariefdien@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

14 December 2018

HREC REF: 646/2018

Ms L Ganca
Public Health & Family Medicine
Entrance 5, level 2
Falmouth Building-FHS

Dear Dr Ganca

Thank you for your response letter, addressing the issues raised by the Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30 December 2019.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate Institutional approval, where necessary, before the research may occur.

Yours sincerely

PROFESSOR M BLOCKMAN

Federal Wide Assurance Number: FWA00001637.

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines.

The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 312.56 and 312.57.

Appendix B: Approval letter from the Ministry of Health



Ministry of Health
PO Box 514
Maseru J00

RE : ID110-2019

Date: 29 March 2019

To
Tonny Mwabury
Master of Philosophy
candidate University of
Cape Town

Category of Review:

- Initial Review
- Continuing Annual Review
- Amendment/Modification
- Reactivation
- Serious Adverse Event
- Other

Dear Tonny,

RE: Perception of health care worker regarding the need for palliative care service in three (3) elected hospitals in Lesotho

This is to inform you that the Ministry of Health Research and Ethics Committee, after reviewing your proposal, **APPROVED** the proposal and hereby authorize you to conduct the study according to the activities and population specified in the protocol. Departure from the approved protocol will constitute a breach of this permission. This approval includes review of the following attachments:

- Protocol version March 26 2019
- English consent forms
- Lesotho consent forms 2018
- Data collection forms: Question guide in English
- Participant materials: Information in English
- Other materials:

This approval is **ALTD** until March 28 2020.

Please note that an annual report and request for renewal if applicable, must be submitted at least 6 weeks before the expiry date.

All serious adverse events associated with this study must be reported promptly to the MOH Research and Ethics Committee. Any modification to the approved protocol or consent forms must be submitted to the committee prior to implementation of any changes.

We look forward to receiving your progress reports and a final report at the end of the study. If you have any question please contact the Research and Ethics Committee at rcumoh@gmail.com (or) 22226317.

Sincerely

Dr. **Maane Letie**
Director General Health Services

Dr. **Limpho Maile**
Member of H-RE

Appendix C: Approval letter from Tsepong Hospital



TSEPONG (PTY) LTD

Tel: + 266 2222 0000

Private Bag A114, Maseru, 100, Lesotho

REF: "Perceptions of healthcare workers regarding the need for palliative care services in three selected hospitals in Lesotho",

Date of Approval: 29.04.2019

Tonny Mwabury

University of Cape Town

Sir,

LETTER OF AUTHORIZATION TO CONDUCT RESEARCH AT TS'EPONG

This letter serve as authorization of: Tonny Mwabury to conduct the research project entitled:

"Perceptionsof healthcare workers regarding the need for palliative care services in three selected hospitals in Lesotho", at Queen Mamohato Memorial Hospital.

Upon a review of the research proposal sent to the institutional research board, we are glad to offer you an opportunity to conduct the same study in our organization. This approval is based on the fact that the board found it to be ethically sound, and is for 365 days from the date of IRB review and approval.

All interviews, filed surveys, observations around the site and the distribution of questionnaires are approved and will be duly supervised by the Public Relations Office.

Please note that you are expected to submit a copy of the write up of your research to PRO.

If you have any concerns or require additional information, feel free to contact the unit.

Thank you

Sincerely,

A handwritten signature in black ink, appearing to read "G. Wondimagegn", is written over a horizontal line.

Dr. G. Wondimagegn

Chairman of Board

Ts'epong (PTY) It d.

A handwritten signature in black ink, appearing to read "Zondy Mohapi", is written over a horizontal line.

Ms. Zondy Mohapi

General Manager

Ts'epong (PTY) Ltd

Appendix D: Informed Consent Form

Part I: Information Sheet

Introduction

I am a qualified and practicing Medical Practitioner, enrolled in a Masters Course in Palliative Medicine through the University of Cape Town. I am conducting a qualitative study that investigates perception of HCW regarding the need for PC services in three selected hospitals in Lesotho. You are invited to take part in the research study as you have been identified as a key informant in your institution.

What is the purpose of the study?

This study seeks to explore Perception of HCW in three hospitals; to identify the need for PC service and to elicit views on how the burden of the diseases is being addressed. The findings emerging from this study could provide useful insights and a roadmap to assist other hospitals and the Lesotho health system on how to enhance the quality of care in their institutions.

Do I have to take part?

No, you do not have to take part. If you do agree to take part, you are free to withdraw from the interview at any time without giving us any reason. If you do agree to take part, you will be asked to sign a consent form, which shows that you have agreed to do so. You can take some time to think about whether you would like to take part.

What will happen if I take part?

An experienced researcher will interview you and ask you questions about the palliative care services in your institution. The interview may be scheduled in or after working hours (depending on your availability and preference) and will last approximately 30-60 minutes. With your permission, the interview will be recorded using a Digital recorder.

What are the benefits of the study?

There will be no direct benefit to you, but your participation will help the researcher to find out more about the HCWs perception regarding the need for PC services in order to assist government and other hospitals to develop appropriate PC programs.

Will I be remunerated for participating in the study?

You will not receive any compensation for participating in this study.

What are the risks of the study?

You may feel uncomfortable talking about some of the topics such as opinions of colleagues and government policies. You are encouraged to discuss these concerns with the researcher, but you are free to stop your participation at any time of the study at any time. Every effort will be made by the researcher to minimize your discomfort and to ensure confidentiality.

Will my taking part in this study be kept confidential?

Strict precautions will be taken to safeguard your personal information. The information that is gathered from the interview will be stored in locked cabinets, and digital information computer password protected. Only I and my supervisors will have access to the information. The data collected from the interview will be anonymous and confidential; your name will not be attached to the stored information nor used in any publications. Information obtained during the interview, which may reveal your identity, is confidential unless you agree to its release.

How will I know about the results of the study?

A summary of the research findings will be provided to each hospital. The final report will be submitted to the University of Cape Town near the end of 2020, and can be made available to your organization if requested.

The findings will also be shared with Lesotho Ministry of Health and may be used in publications later.

Who can I contact if I have further queries regarding the study?

If you have any queries or concerns, you can discuss them now or later. If you wish to discuss them later, you can contact:

Tonny Mwabury (Researcher) Linda Ganca (Principal Investigator)

M: 0834298928.

tonnymwabury@gmail.com. linda.ganca@uct.ac.za

If you have any questions about your human rights or any ethical issues about the study, contact:

UCT Research Ethics Committee:

Mrs Lamees Emjedi

Research Ethics Committee

E 52 Room 24, Old Main Building, Groote Schuur Hospital, Observatory

Telephone: 021 406 6338

Who is organizing the research?

If you have any questions about the study, you can contact the following people.

Researcher: Tonny Mwabury, Najojo Better Living Missions Association Teya Teyaneng, Berea
+26662989270

Supervisor: Mrs. Linda Ganca, University of Cape Town: +27 21 406 6590

Appendix E: Certificate of Consent

Part II: Certificate of Consent

I have agreed to partake in a research study that aims to investigate perception of HCW regarding the need for PC services in three hospitals in Lesotho.

I confirm that I have read and understand the information sheet and have had the opportunity to ask questions. Any questions I have asked have been answered to my satisfaction.

I have not been coerced into agreeing to partake in this study. I understand that my participation is voluntary and I am free to withdraw at any time, without giving a reason.

I consent for the interview conducted with me to be digitally recorded.

Print Name of Participant _____

Signature of Participant _____

Date _____

Print name of Witness _____

Signature of Witness _____

Date _____

Statement by the researcher:

I have accurately presented or read out the information sheet to the potential participant, and to the best of my ability I have made sure that the participant has understood the information provided.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability.

I confirm that the individual has not been coerced into giving consent, and the consent has been voluntary.

A copy of the Informed Consent Form has been provided to the participant.

Print name of researcher _____

Signature of researcher _____

Date _____

Appendix F: Semi-Structured Interview Schedule

Study title: Perceptions of healthcare workers regarding the need for Palliative care services in three (3) selected hospitals in Lesotho

Introduction: Thank you for agreeing to take part in this study and signing the consent form.

QUESTIONS

1. There is growing evidence that most patients' end of life suffering is influenced more by psychosocial factors than physical³³. Tell me, what is your experience in this hospital and/or your views on this? ... (Objective 1)
2. (Use cues from participant's response) So your experience is.... Tell me, what health conditions/illnesses are presented in your hospital which contribute to high mortality rates in both adults and children? (Objective 3)
3. How are these conditions managed holistically in this hospital, in terms of physical and psychosocial challenges of patients? (Objective 1, 3)
4. Palliative care is an approach that improves the quality of life of patients and their families dealing with a diagnosis of a life-threatening conditions through preventing and relieving their suffering. Can you please explain to me which condition in your view qualify a patient to receive palliative care services (Objective 2, 3)
5. In relation to managing physical pain, what are your views on the availability and accessibility of medication/opioids that are used? (Objective 1, 2)
6. Are there policies and procedures at this hospital on how to manage patients where curative measures have been exhausted including patients who have been diagnosed with a life-threatening condition? (Objective 2)
7. In your experience would you say in this hospital palliative care services are being provided? If Yes or No - Please justify your response (objective 1,2,3)
8. Closing statement: Thank you very much for taking time to contribute valuable information for this study. Once again, I want to reassure you that the information gathered during this interview will not be used in any other way except for the academic purpose of this study.