The perceived needs and challenges of family caregivers in providing palliative care for relatives living with cancer in Hhohho Region, Kingdom of Eswatini.

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KEY WORDS

- Palliative care
- Home-based Care
- Family
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- Cancer
- Challenges
- Support
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ABSTRACT

In 2018 within the Kingdom of Eswatini, there were an estimated 1 074 new cancer cases and 660 cancer-related deaths. For some time, there has been a growing trend away from the provision of palliative care within an institutional setting to providing palliative care to the patient within the context of their own home. As a result, the majority of dying patients spend their final days at home with much of the care being provided by family caregivers. In Eswatini, little is known about the impact that managing a terminally ill patient has on the family caregiver and whether they experience receiving sufficient support from the local health services. This study aimed to explore the needs and challenges of family caregivers in providing palliative care for their relatives living with cancer in Hhohho Region, Kingdom of Eswatini.

This exploratory, descriptive study used a qualitative research approach. A purposive sample of ten family caregivers from peri- urban and rural communities within the region were selected. Data was collected through semi-structured interviews in the homestead of participants. Thematic analysis was used to analyze the data. In terms of ethics, informed consent was sought from each interviewee and they were informed of their rights to not participate or to stop participating at any time, without any negative consequences to them. If any participant needed counselling, a counsellor was available to them.

The study revealed that caregivers have a number of unmet needs as home-based caregivers, with a priority on a need for better information and preparation in anticipation of their role as a caregiver and a need to receive some form of counselling support. There were a number of challenges which caregivers identified as impeding the quality of care at home. These include a sense of uncertainty about their own future after the death of the family member, lacking the time to manage their own health (the ‘Care for the Carer’), insufficient finances and not being able to adequately engage with healthcare workers at various health facilities. Moreover, local health facilities are frequently lacking essential pain medication (morphine) and basic home-based commodities (such as gloves and adult diapers) which are needed to provide quality care in the home environment.

Support for family caregivers providing palliative care is essential and the recommendations from the study promotes a health care system that includes caregivers in treatment of patients with cancer.

DECLARATION

I declare that the work presented herein; The perceived needs and challenges of family caregivers in providing palliative care for relatives living with cancer in Hhohho Region, Kingdom of Eswatini is my own work and it is original. It has not been submitted for any degree or examination in any other university or institution for the award of a degree or certificate. All sources of information and data used or quoted have been duly indicated and acknowledged by complete reference.

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Signature: Mamba Dated: 26 March 2021

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LIST OF ABBREVIATIONS

GLOBOCAN	Global Cancer
HBC	Home Based Care
MOH	Ministry of Health
NCD	Non-communicable Disease
NGO	Non-governmental Organization
RHM	Rural Health Motivator
SSA	Sub-Saharan Africa
WHO	World Health Organization

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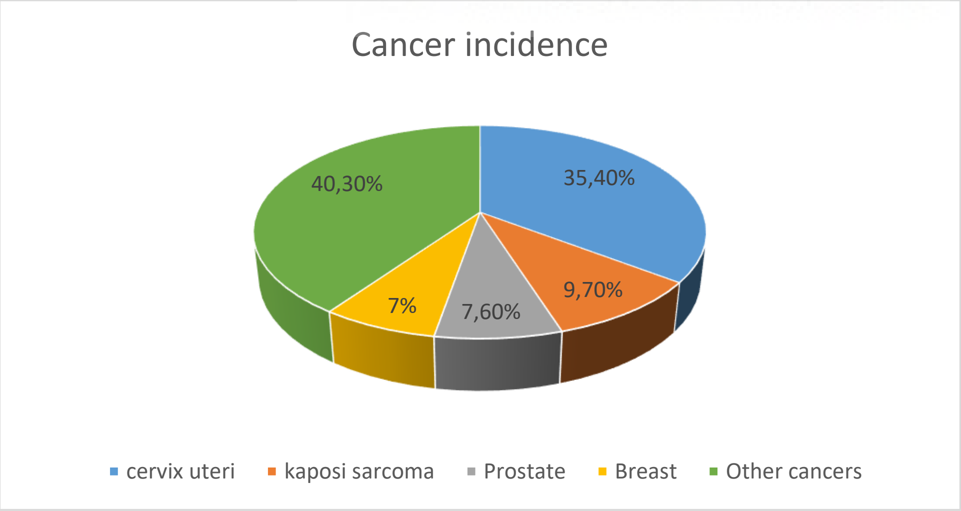
CHAPTER 1: INTRODUCTION

1.1. Background

Cancer is one of the leading causes of morbidity and mortality worldwide (World Health Organization [WHO], 2018). In 2018, there were 18.1 million new cancer cases and 9.6 million deaths (WHO, 2018). In the same year in Africa, there were an estimated 8 million new cancer cases and 5.3 million cancer-related deaths (GLOBOCAN, 2018). More than two thirds of new cancer cases and cancer deaths worldwide occur in low and middle-income countries where such numbers are increasing at alarming rates (World Cancer Research Fund, 2018). In the Kingdom of Eswatini, in 2018, there were an estimated 1 074 new cases of cancer reported through both public and private health facilities and 660 cancer-related deaths (Eswatini National Cancer Registry, 2018). The 2018 National Cancer Registry Data indicates a high incidence of cervical cancer and such cancer is the leading cause of mortality among cancers affecting the population of Eswatini as indicated in Figure 1 below.

Figure 1: Cancer Incidence in Eswatini



Source: Eswatini Cancer Registry, 2018.

Morbidity associated with cancer obviously gives rise, in many cases, to the need for palliative care for those affected and each year an estimated 40 million people are in need of palliative care worldwide (WHO, 2018). Among these, 78% are living in low- and middle-income countries and the need for palliative care is thus a significant one within an African context (WHO, 2018).

Palliative care is an approach that improves the quality of life of patients and their families who are facing problems associated with life threatening illnesses (WHO, 2018). Palliative care is not only offered in health facilities but patients needing palliative care receive it even within the context of their own home. Insufficient health care services leave families with no option but to be extremely involved in providing care for family members (Kristanti *et al*., 2019). As a result, the majority of dying patients spend their final days at home with much of the care being provided by family caregivers (Stajduhar, Martin & Barwich, 2008).

Not unexpectedly, the new role of providing care within the home, with little or no experience of caring for terminally ill patients, comes with potential challenges for family caregivers – some of which might be unanticipated. For example, Becque *et al*. (2019) notes that family caregiving may give rise to various negative health consequences. These can range from physical and emotional challenges such as sleep disturbances and anxiety, to social and financial challenges such as lack of time for socializing and loss of savings (Harding *et al*. 2012). Girgis *et al.* (2013) noted that family caregivers often take up the caring role ignorant of the demands that will be placed on them and what their role will entail. These unanticipated challenges often make it difficult for family caregivers to cope with the new responsibility of providing end-of-life care for their family member within the context of their family home.

1.2. Problem Statement

In Eswatini the public health facilities do not offer home-based palliative care. The public health system relies on family caregivers to provide 80% of care that chronically and acutely ill patients with cancer receive (Goldsmith & Ragan, 2017). In the country, home-based palliative care is provided by non-governmental organizations (NGOs) that provide support to the families of patients with cancer. Despite such care being provided in the home throughout Eswatini by NGOs, little has been documented about the experiences that the family caregivers of cancer patients face in caring for their terminally ill family member. Family caregivers of cancer patients have needs and challenges which require some support so as to cope with the role of caring (Harding *et al*., 2012). Whether family caregivers within communities are sufficiently skilled to manage their terminally ill relatives at home is also unclear. Of particular concern is that little is known about the impact that managing a terminally ill patient has on the health of the family caregivers themselves. As a result of this gap in knowledge, the needs of the family caregivers are not always adequately considered in future planning processes: by both the Ministry of Health and its Non- profit Organization partners within the country and specifically within the study setting.

1.3. Study Setting

Hhohho is one of the four administrative regions in the Kingdom of Eswatini. It is the second most densely populated region in the country (Ministry of Health, 2016) and is the region in which the country’s national referral hospital is based. Because of this, it is where the majority of the country’s cancer diagnoses are made and where patients requiring end-of-life care are referred from and back into their home communities. In 2018 there were 246 patients diagnosed with cancer in the Hhohho region that required home-based palliative care (Eswatini National Cancer Registry, 2018). There is currently only one non-governmental organization (referred to in this thesis as NGO AB) which makes monthly home-based visits to cancer patients in the Hhohho region. Community clinics within the region do not have transport to do home-based visits to patients who are terminally ill. These clinics also lack home-based care commodities like adult diapers, which are essential when taking care of many of the end-of-life patients.

1.4. Purpose of Study

The purpose of this study is to gain an in-depth understanding of the day to day experiences of family caregivers and the particular needs and challenges they face in providing home-based palliative care to their family members who are terminally ill with cancer. It is hoped that the study findings will provide information for evidence-based decision making amongst various stakeholders within the Ministry of Health such as the Hhohho Regional Health Management Team, the palliative care units and health facility managers of community clinics within the region and the local non-profit organizations working within this arena. It is hoped that these findings will ultimately contribute to the development of training programmes that would assist caregivers in the management of relatives living with cancer within a home environment across Eswatini.

1.5. Outline of the Report

This mini-thesis consists of six chapters. The first chapter puts the study into context. In the second chapter, a review of the literature related to the needs and challenges of family caregivers in providing palliative care is presented. The third chapter describes the methodology that was used to carry out this study. The fourth chapter presents the results of the study and the fifth chapter presents an analysis, discussion and interpretation of the results. Conclusion and recommendations drawn from the study are presented in the sixth chapter.

CHAPTER 2: LITERATURE REVIEW

2.1. Introduction

This literature review provides insight on the reported needs and challenges of family caregivers in providing palliative care for their relatives living with cancer. It also considers the impact that caring for a family member has on family caregivers. Needs highlighted in the literature include the need for the family caregiver to be prepared for caregiving, the need to be visible to health care workers, the need for information about the course of illness and the need for emotional support for family caregivers. The key challenges identified include uncertainty about the caregiver's future after the death of the patient, the experience of distress in witnessing the patient deteriorate, the challenge of having minimal or no financial support and the challenge of lacking time to manage their own illness or health as caregivers.

2.2. Health System of Eswatini

Eswatini is a lower middle-income country in Sub-Saharan Africa with a formal and informal health sector. The informal sector consists of traditional health practitioners and other unregulated service providers like prayer people who use holy water and/ointments to treat people. The formal sector is the one based on Western Medicine and consists of public and private health services. Health system delivery in the country is through three levels: primary, secondary and tertiary levels. Community based health care workers are within the primary health care level, together with clinics and outreach sites. The secondary health care level consists of health centres and public health units while the tertiary level comprises regional referral hospitals and specialized hospital. Hhohho Region has the same health system like the other Regions in the country, with the addition of the National Referral Hospital where most cancer diagnosis are made. The government of Eswatini is involved in assisting people with cancer to access treatment. It has set up Phalala Fund which assists deserving Swati citizens *who* would otherwise not have access to specialist medical care, to secure such care either within the Kingdom of Eswatini or in special circumstances, outside the Kingdom of Eswatini (MOH, 2018).

Like most African countries, Eswatini health sector faces human resource demands but it is supplemented by Rural Health Motivators (RHMs). Eswatini has under its ministry of health an RHM program which was established in 1976 before the Alma Ata Declaration of 1978 and the WHO initiative of the Universal Access to Health Care (MOH, 2016). RHMs in the country are very instrumental in the delivery of primary health care and are able to work with hard to reach communities, delivering home based care (HBC). HBC improves the quality of life for chronically ill patients at home.

After the first HIV case was diagnosed in 1986 in the country, there has been an increase in the disease burden due to HIV epidemic (MOH, 2018). In addition, the country is battling with non-communicable diseases (NCDs) like heart disease, stroke and cancer, among others (MOH, 2018). Patients suffering from NCDs are cared for within communities and RHM's have been trained on emerging diseases thus they are able to support family caregivers within the home environment when possible. Caring for a patient in the home has its own challenges which require working in collaboration with health partners for positive outcome.

2.3 The Needs of Family Caregivers

2.3.1 The need for preparation for caregiving

Harding *et al*. (2012), in their qualitative study conducted in London, United Kingdom, on the perceived needs of family caregivers providing home-based palliative cancer care, found that caregivers have a need for some form of preparation in caring for a relative with cancer. Among the sample of 20 family caregivers who participated in semi-structured interviews, some reported that they wished someone would give them some tips and advice on how to manage common problems and symptoms (Harding *et al*., 2012). For example, one caregiver stated "…how to make him more comfortable and help him with the pain…I can't help with the physical stuff" (Harding *et al*., 2012: 1977).

Mazanec *et al*. (2018) concurs with the view of the importance of "feeling prepared" amongst caregivers. They conducted a quantitative study using a convenience sample of 50 male caregivers in the United States, on the perceived needs, preparedness and emotional distress of male caregivers who were providing home-based care to female cancer patients. It was revealed in this study that caregivers commonly felt unprepared and lacking the required skills to undertake the broad scope of clinical caregiving tasks that they were expected to manage.

A further study conducted by Henriksson & Stedt (2013) with 25 family caregivers using a cross-sectional design in Stockholm, Sweden, on factors associated with preparedness for caregiving within the family also provides support to the view of preparedness for caregivers. They found that family caregivers often reported feeling inadequately prepared to handle the caregiver role, including being able to manage symptom control and the management of medications, among other care activities (Henriksson & Stedt, 2013). The authors put forward that preparedness in cancer caregivers mostly, is a variable that may actually *protect* family caregiver's wellbeing (Henriksson & Stedt, 2013).

Kehl *et al*. (2015) in their qualitative study conducted in the United Kingdom and focusing on how hospice staff members prepare family caregivers for the patient's final days of life found preparedness to be an important factor in caregiving. Family caregivers who reported being prepared for caregiving described more positive outcomes – such as perceived capability, having their information needs met, and describe higher levels of hope. Similar to the other studies that have been described before (Kehl *et al*., 2015), the authors also suggested that a lack of preparedness was linked with "caregiver fear, anxiety, anger, fatigue, lack of adjustment, feelings of helplessness, lack of confidence about their caregiving abilities and depression" (Kehl *et al*., 2015: 132). Holm *et al*. (2014) make an interesting point: that caregiving preparedness is not something that is necessarily done beforehand to develop capabilities but has to take place continuously, throughout the course of the illness. These authors further emphasize that since preparedness is an important factor of family caregiver health and well-being, it should be an important consideration for health professionals to know how to promote a sense of preparedness in family caregivers who are providing palliative care in the home (Holm *et al*., 2014).

2.3.2 The need to be visible to health care workers

Interestingly, another need of family caregivers that was identified by Harding *et al*. (2012) in the palliative cancer care environment is that their caring role be acknowledged by health care workers. A qualitative study conducted in Canada with 29 purposively selected family caregivers providing end-of-life cancer care at home, emphasized that family caregivers feel that they take on a lot of the care that has to be provided by nurses in health facilities, and they thus feel that their role in caregiving should be recognized and appreciated by health professionals (Stajduhar, Martin & Barwich, 2008). One caregiver shared in this study:

> "We all think we can do it [caregiving at home] but it is a lot, it does not matter how bad it is, I try not to get discouraged… health professionals should see our role in caring for the patient…" (Stajduhar, Martin & Barwich, 2008: 80)

Similarly, Wittenberg-Lyles (2012) in a qualitative study conducted in the United States on stress among caregivers found that family caregivers reported feeling frustrated with health care workers in hospitals in the lack of acknowledgement they gave to their role as primary caregiver. Linderholm and Friedrichsen (2009), in their qualitative study which looked at family caregivers' experiences of their caring role in palliative home care found that family caregivers similarly felt left out and experienced a sense of powerlessness when they did not manage to develop a relationship with healthcare workers that were providing clinical care for their family member.

Linked to this sense of visibility, Harding *et al*. (2012) suggests that health professionals should also recognize caregivers – not only as providers of care but as potential recipients of care since their needs sometimes even exceed those of their patients. These authors further note that by offering greater support to family caregivers, the health professionals will in turn be supporting those who are chronically ill with cancer – and who depend on their family member to be sufficiently robust to support their palliative care needs (Harding *et al*., 2012).

2.3.3 The need for information about the course of illness

Family caregivers also have very practical needs, like, for example, they need basic information about the disease and its likely progression. A study conducted in Germany using a literature review of 12 papers (4 having qualitative design, 7 having quantitative design and 1 mixed method paper), which focused on the unmet needs of palliative caregivers reported the shortage of information that was given to caregivers regarding disease progression, symptomatology, available support services and financial services (Nasrullah, 2017). Harding *et al*. (2012) in their qualitative study conducted in London, United Kingdom, on the perceived needs of family caregivers providing home-based palliative cancer care with 20 family caregivers supports this finding and state that home-based carers of dying patients with cancer have a huge need for more information on the prognosis, the progression of the illness and about the treatment that is being provided to their family member. In a qualitative study conducted in the United States, caregivers also reported the need for more information on those under their care with special mention being made of them requiring information about physical caregiving techniques such as proper techniques for moving patients and symptom recognition (Wittenberg-Lyles, 2012).

Interestingly, Hudson (2009) in a study conducted in Melbourne, Australia on home-based support for palliative care families noted that some family caregivers feel doubtful to ask for information from health care workers since they consider them to be very busy and do not want to bother them. The author also noted that information about dying is sensitive and emotionally-charged and health care workers might want to avoid discussing it and deprioritize it (Hudson, 2009), with the result that some vital information that is *really* needed is not shared with family caregivers. Glajchem (2012) in a review of literature conducted in the United States on physical well-being of oncology caregivers found that information can help normalize the caregiver experience and promote a sense of control as caregivers gain knowledge on what to expect during the course of the illness.

2.3.4 The need for emotional support for caregivers

Caring for a family member also places both a physical and psychological strain on a family carer (Gotze *et al*., 2014). Thus, another need of family caregivers is the need for emotional support as taking care of a dying relative can deeply affect one psychologically (Harding *et al*., 2012). A family caregiver in this study shared:

> "I just felt quiet alone and if there was someone that you could just talk to…if there was someone that you felt or knew that you could phone up…" (Harding *et al*., 2012: 1978).

A qualitative study conducted in Canada with 23 caregivers on family caregiver's perceptions of palliative care in home and unit supports the view of emotional support for caregivers as it was revealed that caregivers cope better if they perceived adequate support during the caring period (Lessard, Leclerk & Mongeau, 2014).

Steel and Davies (2015) in a qualitative study conducted in the United Kingdom on supporting families in palliative care states that family caregivers may also feel supported in their role merely by knowing there are resources and support accessible to them, even if they do not make use of these resources.

In order for family caregivers to manage the extensive demands placed on them, caregivers not unsurprisingly rely on those close to them for support, for example, other family members and friends. A qualitative study conducted in the United States on end-of-life caregiver support revealed that the 61 caregivers interviewed depended on family members and friends for emotional support in the form of encouragement, empathy and sympathy (LaValley, 2017). However, Hudson (2009) in a qualitative study notes that having an illness like cancer affects family relationships such that communication within the family decreases and the burden of taking care of the terminally ill patient is exhausting, something which can easily aggravate already strained relationships and communication patterns.

Despite the potential difficulties that might exist between family caregivers and health professionals, for example, that they neglect to acknowledge the work of the family caregiver – where health professionals *are* available to support family caregivers, they were identified as a much-needed form of support by family caregivers in a number of studies. Professional assistance was reported as providing a strong sense of security for the family caregiver and the ill person in Canada in a study conducted by Lessard, Leclerk & Mongeau (2014) on family caregiver's perceptions of palliative care in home and unit. These authors noted that a strong relationship between health professionals and family caregivers can be an important source of support for caregivers (Lessard, Leclerk & Mongeau, 2014). The possibility of being able to reach out to health professional brought caregivers a sense of security, reliability and comfort, LaValley (2017) reported – with the knowledge of support *being available,* on its own, a type of support in itself.

2.4 The Reported Challenges of Family Caregivers

2.4.1 The challenge of an uncertain future after the death of the patient

One of the challenges reported by family caregivers is that of uncertainty, as they worry about their future and the future of their sick relative. Harding *et al*. (2012) in their qualitative study conducted in London, United Kingdom, with 20 family caregivers on the perceived needs of family caregivers providing home-based palliative cancer care reported that family caregivers were worried about the future once their dying relative passes on. One caregiver shared in this study:

> "The council will move me from here…If he dies, they want this place so I have to move…where will I live...my whole life will just completely change…" (Harding *et al*. 2012: 1979).

Worry about the future is understandable where family caregivers are financially dependent on their dying relative and have to plan how they will survive once their relative passes on. The thought and fear of being alone, without their support, understandably represents an uncertain future for many family caregivers. A qualitative study conducted in Ghana with 23 female caregivers on exploring caregivers' experiences of caring for men with advanced prostate cancer found that wives and partners had a fear of an unknown future (Salifu, Almack & Caswell, 2018).

Family caregivers are not only worried about the future after their family member has passed on but they also worry about the practical aspect of their family member dying in their presence. A qualitative study conducted in London, United Kingdom, with 20 family caregivers on the perceived needs of family caregivers providing home-based palliative cancer care specifically found that some family caregivers did not want to be present when their relative died (Harding *et al*. 2012). Similarly, Henriksson and Stedt (2013) in their Sweden study conducted with 125 family caregivers of patients with life-threatening illnesses found that family caregivers who had had little exposure to death and dying, feared seeing their relative die in front of them.

2.4.2 The experience of distress among caregivers

Bee (2009) in a review of literature conducted in the United Kingdom on caregivers' needs in providing home-based end-of-life care to people with cancer reported distress as another challenge experienced by family caregivers. They reported being distressed at witnessing their relative deteriorate, despite all their efforts to make him/her improve (Bee, 2009). Henriksson and Stedt (2013) in their Sweden study conducted with 125 family caregivers of patients with life-threatening illnesses supports this view as they found that family caregivers are likely to be distressed as the cancer advances, with a loss of physical function and more complicated care needs. Caregivers added in another study being distressed by the side effects of some of the medication that some cancer patients were having to take (Harding *et al*., 2012).

Some family caregivers report sadness, sorrows and exhaustion as most distressing (Ullrich & Asherfield, 2018). A qualitative study conducted in the United States with 61 caregivers on end-of-life caregivers found that caregiving involves a lot of emotionally and physically challenging tasks which leave a caregiver at an increased risk for anxiety, depression, and injuries related to providing care at home (LaValley, 2017). A further study done in the United States on stress among family caregivers found that caregiving duties are time consuming and overwhelming, all of which compound the caregiver's susceptibility to clinical levels of depression (Wittenberg-

Lyles, 2012). Krug *et al*. (2018) in a qualitative study done in Hiedelberg, Germany with 19 care providers on challenges in supporting caregivers of patients at the end of life supports this view as they found that caregivers develop psychological symptoms like depression and anxiety, they experience stress due to caregiving.

2.4.3 The challenge of having minimal or no financial Support

Gotze *et al*. (2014) in a survey conducted in Germany with 106 family caregivers identified another challenge: that of the financial strain that family caregivers face when caring for a terminally ill cancer patient. For example, financial strain can be placed on the household when a patient has to be taken to and from health facilities for consultations and/or treatment; or when the family has to purchase additional and specific medications which are not available for free in health facilities; and when the family is encouraged to purchase particular types of foodstuff in order to promote the nutrition of their dying relative (Gotze *et al*., 2014). A systematic review of 51 qualitative articles on end-of-life care in sub-Saharan Africa supports this view as it was discovered that providing appropriate food, medicines and water financially impoverishes carers (Gysels *et al*., 2017).

In addition, apart from the direct costs, Girgis *et al*., (2013) in their study conducted in Melbourne, Australia, reported that caregiving can lower a person’s chances of being employed, given the demands placed on that carer in terms of the time required to be at home managing the patient (Girgis *et al*., 2013). McAllister (2013) notes that when caregivers have to take time off work to attend to the ill family member, this also contributes to the financial stress that the household is placed under.

2.4.4 The challenge of lacking sufficient time to manage their own health as caregivers

Cancer caregiving includes significant physical strain, as the patient's disease and treatment-related symptoms increase, the cancer caregiver suffers from caregiving-related symptoms and physical well-being decreases (Ferrell, 2017) thus caregiver health is another challenge for family caregivers. It was revealed in a qualitative study conducted in Canada with 29 purposively selected family caregivers providing end-of-life cancer care at home that up to 50% of palliative care family caregivers reported chronic illnesses of their own (Stajduhar, Martin & Barwich, 2008). Family caregivers experience health problems like depression, back pain, poor mobility, ulcers and heart disease (Harding *et al*., 2012). Family caregivers also report psychological morbidity during the total disease process of the patient (Oechsle, 2019).

A review of literature conducted in the United Kingdom on preparing for family caregiving in specialized home care found that additional duties of caring among caregivers, results in negative effects on their health and well-being such as stress, anxiety, fear, guilt and sleep disturbances (Holm *et al*., 2014). Sleep disturbance was found to affect caregiver's ability to grasp and retain information in a qualitative study conducted by Hudson (2009) in Melbourne, Australia.

Caregiving also affects social connectedness and the regular activities as a caregiver's energy and time tend to be focused on the patient and their recovery (Girgis *et al*., 2013). Stajduhar, Martin and Barwich (2008) in a qualitative study conducted in Canada with 29 purposively selected family caregivers providing end-of-life cancer care at home supports this view as they state that family caregivers lack control over their everyday lives, have limited leisure time and disrupted personal routines.

Krug *et al*. (2018) in a qualitative study conducted in Hiedelberg, Germany with 19 care providers on challenges in supporting family carers of patients at the end-of-life found that family caregivers often dedicate a huge part of their time (on average 37 hours per week) to care of a patient, which leads to social isolation and higher perceived caregiver burden (Krug *et al*., 2018).

2.4. Summary of the Literature Review

In summary, it is clear from literature that needs and challenges of family caregivers providing palliative care have been studied to a greater extent in developed countries but in lower- and middle-income countries like Eswatini, such issues have not been studied. Literature has proven that family caregivers of cancer patients share similar experiences in their caregiving journey. Providing palliative care is a burden that literature has proven to disrupt lives of family caregivers and requires that caregivers receive support. Exploring the needs and challenges of family caregivers providing palliative care adds knowledge to the field of palliative care since a few studies have been conducted in lower- and middle-income countries (particularly SSA).

CHAPTER 3: METHODOLOGY

3.1 Introduction

This chapter presents a description of the methodology used to conduct the study. It sets out the aim and objectives of the study and the study design. It then describes the study population, sampling procedures and the way in which the study was introduced within the local context. The qualitative methods used to collect and analyze data are outlined along with considerations related to rigour and ethics. Finally, the limitations of this study are presented at the end of this chapter.

3.2 Study Aim and Objectives

The aim of this study was to explore the needs and challenges of family caregivers in providing palliative care for relatives living with cancer in the Hhohho Region, Kingdom of Eswatini.

The three objectives of the study were as follows:

1. To explore and describe family caregivers' needs in providing palliative care for relatives living with cancer.
2. To explore and describe the various challenges family caregivers face in providing palliative care for relatives living with cancer.
3. To explore and describe the kind of support family caregivers would find most beneficial to receive from local health professionals within the Ministry of Health and non-profit organizations when providing palliative care for relatives living with cancer.

3.3 Study Design

This was an exploratory, descriptive qualitative study, suited to bring new insight on a phenomena about which little is known (Polit & Beck, 2009). A qualitative approach is useful in gaining knowledge behind human opinions, perceptions, values and experiences (Yilmaz, 2013). Given that the aim of the study was to explore the experiences and recommendations of family caregivers, the approach seemed most appropriate for this study. The flexible nature of such an approach allows participants to respond freely to questions and express their views openly - and in their own words (Polit & Beck, 2009). Therefore, using a qualitative - as opposed to a quantitative research approach - enabled the researcher to explore in greater depth experiences and perceptions of family caregivers.

3.4 Population and Study Sample

The study population were family caregivers above the age of 18 years, who had been directly involved in taking care of their family member for a duration of more than 6 months. In the event a family caregiver had lost their family member to cancer, this was loss that had occurred in the past 18 months. Time periods were chosen since 6 months was a long enough duration for a caregiver to know needs and challenges while 18 months was a duration which allowed for recall of needs and challenges. The focus was on family caregivers living within the Hhohho region, Eswatini.

The researcher used purposive sampling to select study participants. Purposive sampling provides a researcher with the opportunity to hand-pick study participants that will benefit the study based on personal judgment. It allows for selection of study participants that are most informative and provide rich information (Polit & Beck, 2009). All participants had experienced the phenomenon under study and were able to articulate what it was like to have lived that experience (Polit & Beck, 2009).

Selecting study participants was not a difficult task for the researcher who is a palliative care nurse within the region and works in collaboration with the palliative care department at the National Referral Hospital. The researcher as an employee of Eswatini Hospice at Home for four years has experience in working with family caregivers when offering home-based palliative care within the region.

Familiarity with documentation like the cancer register in the department of palliative care proved beneficial in selecting the study sample. The cancer register which is kept within the palliative care department in the National Referral Hospital is used to document cancer patients who receive morphine from the Hospital. With the assistance of the nurse manager in the palliative care department within the National Referral Hospital, and using the inclusion criteria, the researcher purposively selected caregivers associated with 10 registered cancer patients living within the Hhohho Region. To achieve a high degree of variation of experiences, purposive sampling was done from the sub-categories decided by the researcher. A sample of ten male and female family caregivers from both peri-urban and rural areas, representing different familial relationships (for example, a spouse, a parent, a child) and living in a variety of socio-economic contexts was identified.

Once the initial sample of 10 potential participants had been identified at the end of May, the palliative care nurse manager contacted participants telephonically to inform them about the study. The nurse manager was guided by the participant information sheet to clearly explain the study to participants and the researcher was present during telephonic conversations. Since participants were familiar with the nurse manager, she made it clear that they were not obligated to participant in the study. Female participants were willing to take part in the study while most male participants reported to be not actively involved in caregiving thus they did not meet the criteria. As a result, the final sample consisted of eight female caregivers and two male caregivers. The nurse manager informed participants that the researcher would contact them to set up a date suitable for them (participants). The researcher left the nurse manager with a list of participants who had agreed to take part in the study.

3.5 Research Guidance in the Context of the COVID 19 Pandemic

The COVID 19 pandemic did not negatively affect this study. When the country went into lockdown, the researcher was awaiting a response from the Eswatini Health Research Review Board. The researcher, as a front-line worker continued to make home visits within the region despite the lockdown. The researcher was granted permission since this study had no risk of increasing transmission of COVID 19 and there was no direct contact with human participants expected to take place during the study. The researcher was expected to comply with health regulations and ensure not to facilitate the spread of the corona virus infection. The researcher managed to conduct the study in the home environment of participants while ensuring the health guidelines in preventing transmission of COVID 19. Participants were also knowledgeable about the COVID 19 virus and observed ways of preventing transmission like wearing their masks. Also, at the entrance of homesteads, there were containers filled with a mixture of water and liquid soap for anyone to wash their hands safely before entering the homestead. Water containers were designed like taps so that water is running when used.

3.6 Data Collection Methods

A semi-structured interview guide was used to conduct in depth interviews (Annexure 5 & Annexure 7). Semi-structured interviews allow participants to respond in their own words and provide as much details about the topics in the interview guide (Polit & Beck, 2009). The interview guide included information such as age, gender, area, employment status, educational level, number of persons living in household and relationship of each of these to the patient. Then there were three sections in the interview guide, with the first section related to the patient's journey (from diagnosis to treatment), the second section was related to the palliative care phase and the last section was about providing home-based care. The researcher used probes to get in depth information and clarity on issues related to the objectives.

All the 10 interviews took place in the homesteads of the family caregivers. The box below (Box 1) describes the typical context in which these interviews were conducted.

Box 1 Summary of the Interview Context

Interviews took place in homesteads of participants located in peri-urban areas and rural. Interviews were conducted outside the house of each participants (where it was quieter and more private). For example, participants from the peri-urban areas would prefer sitting on the verandas of their houses while participants from rural areas preferred a shelter nearby their house (like under the shade of a tree). Other household members were careful not to interrupt the interview process and where necessary, during the course of the interview, they took responsibility for the patient.

In terms of the actual houses, peri-urban houses were generally bigger than rural houses (e.g. they generally had 4 or more rooms whilst the rural houses were only one roomed).

During all the interviews, COVID-19 basic safety protocols were observed like social distance of 1 metre or more, the wearing of masks and the use of sanitizer brought by the interviewer.

At the start of each interview, the purpose of the study was explained to participants using the participant information form (Annexure 1 & 2) and their voluntary informed consent was obtained (Annexure 3 & 4). Permission to record the interview via audio was requested and participants were not hesitant since their names were not mentioned. The interviews were conducted by the researcher in Siswati, which is the indigenous or local language which is spoken in Eswatini. Each interview averaged 40 minutes and interviews were conducted over a period of 6 weeks. Participants were not given stipend for transport or refreshments since interviews took place in their homes.

3.7 Data Analysis

During data collection, analysis was ongoing as the researcher noted emerging patterns from each interview. This allowed the researcher to focus and further investigate noted patterns in subsequent interviews. Once data collection was over, thematic analysis was used to analyze data and the researcher familiarized herself with the data (Pope, Ziebland, & Mays, 2000).

Familiarization was done through listening to the audio recording of each interview, transcribing each, and reading and re-reading every transcript (Pope, Ziebland, & Mays, 2000). Transcripts were shared with the supervisor. Working collaboratively with the supervisor, the researcher then organized data into meaningful groups and patterns from which key themes relevant to the research question were identified and drawn together. It was from fully worked out themes that the researcher provided explanations for findings. Data was analyzed manually.

3.8 Rigour

Quality in qualitative research is a concern for qualitative researchers (Polit & Beck, 2009). To ensure credibility in this study, the researcher chose these strategies: Leaving an audit trail, the process of member checking, the use of researcher reflexivity, space triangulation and the use of thick rich descriptions (Polit & Beck, 2009).

Leaving an audit trail proved to be beneficial in this study. An audit trail makes explicit key research decisions (Cresswell & Miller, 2000) that were made or changed by the researcher during the process. For example, the researcher ended up interviewing more female participants than male participants – something that was not planned. The reasons for such a change were documented and are described in this study in Section 3.4.

The process of member checking was used in this study since the researcher wanted to accurately represent experiences and opinions of caregivers. Member checking was done in an ongoing way as data was being collected. Member checking allows participants to react to emerging data and interpretations (Polit & Beck, 2009).

The use of researcher reflexivity was also employed in this study since the researcher is palliative care nurse within the region. This is a factor that could lead to researcher bias. Therefore, the researcher kept a diary to record personal thoughts, observations and experiences during the study process. These were used by the researcher to remain aware of own biases, preferences and preconceptions as a data collector. Reflexivity allows a researcher to reflect on their own behaviour and how it can affect the data they obtain (Polit & Beck, 2009).

The researcher collected data from multiple sites (i.e. peri-urban[1] and rural[2] communities) to serve the purpose of triangulation and in this study, data triangulation. Data source triangulation is when two different independent data sources are used and this might be in time, if the data is gathered at different points in time, or in space, if the data is gathered at different physical locations (Carter, 2014). Collecting data at different sites allowed the researcher validate the data by testing for cross-site consistency (Polit & Beck, 2009).

Although the aim of qualitative research is not to reach generalizable conclusions, the researcher provided a thick descriptions of research settings, demographic and study participants to allow consumers of research determine transferability of findings to other contexts.

3.9 Ethical Issues

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[1] Peri-urban is an area that is located immediately adjacent to a city or urban area, it is neither urban nor rural (Weeks, 2010).

[2] Rural area is an open area of land that has few houses or other buildings and not very many people, it is far from urban areas (Weeks, 2010).

Ethical clearance was obtained from the University of Western Cape Biomedical Research Ethics Committee and Eswatini Scientific and Ethics Committee. Some of the participants were illiterate and the researcher allowed a literate relative chosen by the participant to read the participant information sheet (Annexure 1 & 2) to ensure that participants understood the purpose of the research and that participation in the study was voluntary. The same applied when informed consent form (Appendix 3 & 4) had to be signed, illiterate participants signed with a symbol X and their literate relative would sign as witness. Participants understood their rights to not participate or to stop participating at any time, without any negative consequences to them. Consent forms and information sheets were available in Siswati for participants.

The researcher was careful to note safety of participants, even though in this study it was not anticipated that any harm would occur. Nevertheless, the researcher minimized risks and had a professional counselor on stand-by for those that might need further assistance or intervention. None of the participants were referred for further counselling.

Confidentiality was observed in this study as information was kept in a locked filing cabinet and on password protected computer files. The identity of participants was protected as well.

3.10 Limitations

Like most qualitative studies with small sample size, findings cannot be applied to a broader population. Participant characteristic limits this, for example, the study had 20% male caregivers and more participants were parents. Living in a rural or peri-urban area did not bring a difference in experience. Also, recall bias was a limitation since participants who had lost their loved one were not able to retrospectively remember certain information with accuracy when reporting their experiences. In-depth interviews were flowing except when participants had to respond to a question requiring what they expected or assistance they would find most beneficial to receive from local health professionals within the Ministry of Health and non-profit organizations when providing palliative care for relatives living with cancer. It is not clear whether participants did not understand the question or they were not expecting any form of assistance from the said sectors. This question did not bring rich insight as expected. Also, due to the researcher being a palliative care nurse within the region, it is possible that participants may have given social desirable responses and this was dealt with through the process of reflexivity.

CHAPTER 4: FINDINGS OF THE STUDY

4.1 Introduction

This chapter presents the main findings from the narratives of the 10 semi-structured interviews that were conducted between May – June 2020. The chapter starts with a summary of the demographic characteristics of the 10 study participants (i.e. the family caregivers). This summary is then followed by a short narrative about each of the study participants, which allows some insight into their socio-economic and familial context. Thereafter, the key results of the interviews are presented in a way that reflects the three study objectives. In other words, what the key needs and challenges were for the family caregivers in providing home-based palliative care to their family member living with cancer, and what support they would have found most useful to have received from the Ministry of Health and other stakeholders during this period.

4.2 Demographic Characteristics of Family Caregivers

The table below (Table 1) summarizes the demographic characteristics of the study participants. The sample included 10 family caregivers, equally split between those who lost their family member and those who were still caring for their family member living with cancer.

Table 1: Characteristics of the 10 Family Caregivers

Characteristic	Number of family caregivers
Gender	

Female Male	8 2
Age range (years)	
20-39 years 40-59 years 60-79 years	2 3 5
Area	
Peri-urban Rural	5 5
Current employment status	
Employed Unemployed Retired	0 9 1
Educational level reached	
Never attended school Primary school High school Tertiary level	4 1 4 1
Relationship of family caregiver to index patient	
Child	3

Spouse Parent	3 4
Duration of their caregiving of the index patient	
1-2 years 3 - 4 years 5-6 years 7 - 11 years	2 2 4 2

As can be seen from the table above, there was a large range in terms of the age of family caregivers (from 27 - 79 years), with the majority being above 60 years of age. Some of the caregivers (2/10) were above 70 years (i.e. Caregiver 1 and Caregiver 10). Family caregivers were primarily female (8/10) and were fairly evenly distributed in terms of their relationship to the palliative care patient, namely, a child, spouse or parent. Most of the family caregivers (6/10) had been caring for their family member for 5 or more years, with the longest being 11 years of caregiving (Caregiver 10, retired elderly man).

Only one of the 10 family caregivers had a tertiary level qualification (Caregiver 10, retired elderly man). The majority of family caregivers had received none or very little formal education (with four participants never having attended school and one only reaching standard 2 of their primary school education). None of the ten family caregivers was currently employed, although one was retired and receiving a pension (Caregiver 10, retired elderly man).

4.3 Description of Family Caregivers

The household and familial circumstances of each of the 10 family caregivers is described below, so as to provide the reader with *some* insight into the context in which the participants were providing home-based palliative care to their sick family member.

Family Caregiver 1:

Is a 70 year old female from a peri-urban area who never attended school. She was caring for her 42 year old daughter who was diagnosed with lung cancer in 2014. Since diagnosis, her daughter received treatment (chemotherapy) in a South African Hospital over a period of 3 years with the assistance of Phalala Fund, which is linked to the Eswatini Government. In the 3 years, she would go away for 2 months and come back home until her treatment was complete.

The 70 year old mother is unemployed and so was her late daughter. The mother reported to have tried selling hand-crafted mats but had to stop since she was not getting any money from this attempt of income generation. They depended on friends of the daughter and neighbours for financial support. Also, the mother reported that her son would occasionally send them money.

She receives an elderly grant of 1500 emalangeni (the equivalent of SA R 1500) every 3 months which helped to some extent. Although she has access to land for farming, due to her age, she was not able to farm anything.

She lost her daughter in May 2020 after having cared for her for a period of 6 years. Her daughter left behind 3 children who are living with their grandmother and an estranged husband.

Family Caregiver 2:

Is a 43 year old male from a rural area who never completed primary education but studied up to grade 4. He was caring for his 36 year old wife who was diagnosed with skin cancer in 2018. When his wife was diagnosed with cancer, her relatives took her to traditional healers and prayer people, against the wishes of the husband. When relatives failed to find treatment for the wife through the traditional way, they allowed the husband to take her to western medical facilities. It was at this time that she received treatment (chemotherapy) for a period of 6 months at Clinic X[3]. In the 6 months, she would go to the clinic every 6 weeks.

The 43 year old husband is unemployed and so was his late wife. The husband reported to be farming crops like maize and rearing cattle as a way of providing food for his family. Also, he would get odd jobs at construction sites to generate income. Neighbours provided support in the form of food parcels to the family.

He lost his wife in May 2020 after having cared for her for a period of 6 years, including the period of 4 years of care before she received her diagnosis in 2018. She left behind 6 children living with her husband.

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[3] Clinic X is a newly opened private owned clinic in one of the country regions which offers cancer treatment (i.e. chemotherapy).

Family Caregiver 3:

Is a 60 year old female from a rural area who never attended school. She is caring for her 43 year old son who was diagnosed with cancer of the penis in 2017. On the day he received his diagnosis, he decided to get circumcised but the process of circumcision made the condition worse. Thereafter, doctors scheduled him for surgery to have his penis removed but he refused and chose traditional ways of treatment. The condition got worse until surgery was no longer a possibility.

The 60 year old mother is unemployed and so is her son. They have a vegetable garden and the mother sometimes gets work in the community fields just to get money to support her family. The mother has another son who assists financially when possible, especially when the sick family member has to go to hospital.

The mother has been caring for her son for a period of 4 years and the son does not have a wife and any children.

Family Caregiver 4:

Is a 48 year old female from a rural area who completed high school (grade 12). She is caring for her 53 year old husband who was diagnosed with cancer of the left eye in 2014. Upon diagnosis, his right eye was already blind. In 2016, doctors at one of the Hospitals in the country decided to remove the left eye so as to prevent the spread of cancer to other parts of the body. This left him completely blind and dependent on his wife. His surgery did not mean he was free from cancer as the cancer had affected surrounding areas thus he had to do chemotherapy in 2017 at a South African Hospital through the support of Phalala Fund. He has been having chemotherapy until the fund stopped paying for his treatment (in 2019) as it was reported that the funds were now insufficient to send people to South Africa for treatment. He would stay for 2 months for treatment at a South African hospital.

The 48 year old wife is unemployed and so is her husband. They have a tractor which has a tanker and supply water within the community and they plant crops like maize and beans in season. They had a relative who used to support them with pain medication but eventually stopped as the relative could no longer afford support of this nature.

The wife has been caring for her husband for a period of 7 years and they have 4 children. The children are not employed and live at home with the parents (two just completed school, one drives the family tractor while the other is still seeking employment).

Family Caregiver 5:

Is a 43 year old female from a rural area who never completed high school but studied up to grade 9. She is caring for her 78 year old mother who was diagnosed with cancer of the cervix in 2016. Since diagnosis, the mother never received any form of treatment and the daughter is not clear on the reasons behind her mother not been given treatment (chemotherapy).

The daughter is unemployed and so is her mother. They depend on an elderly grant of 1500 emalangeni (the equivalent of SA R 1500) the mother receives every 3 months. The mother has a son who works in Mozambique who sends money occasionally to them and a daughter who lives in town and is actively involved when the mother has to be taken to hospital or any health facility.

The 43 year old daughter has been caring for her mother for a period 5 years and is herself the mother of 3 children that live with her in the same household.

Family Caregiver 6:

Is a 67 year old mother from a rural area who never attended school. She was caring for her 39 year old son who was diagnosed with skin cancer in 2018. In 2019 the son was initiated on treatment (chemotherapy) at Clinic X, and was still receiving treatment until he passed away in April 2020.

The 67 year old mother is unemployed and her late son, because he used to work for the correctional services, was able to support his family. The son was not getting monetary benefits from the correctional services but was allowed to use the correctional clinic when he needed to. He used all his savings when seeking treatment and supporting the family.

The mother receives an elderly grant of 1500 emalangeni (the equivalent of SA R 1500) every 3 months. The mother has a vegetable garden which helps towards providing food for the family.

When her son died in April 2020 she had been caring for him for 2 years. The son did not have a wife and children. The mother lives with her unemployed daughter who has returned from her marital home.

Family Caregiver 7:

Is a 27 year old daughter from a peri-urban area who never completed high school but studied up to grade 10. She is caring for her 68 year old mother who was diagnosed with cancer of the rectum in 2019. Since diagnosis, the mother never received any treatment as she was told that the Government of Eswatini is still owing the South African Hospital where she *should* receive treatment – and because of this, the possibility of treatment there is on hold. The daughter could not herself afford to pay for her mother to get treatment in South Africa so her mother has to live with her condition as is.

The 27 year old daughter is unemployed as she had to stop working and move back home to look after her mother who is also unemployed. They depend on an elderly grant of 1500 emalangeni (the equivalent of South African R 1500) which the mother receives every 3 months. Some neighbours assist, when possible, with food parcels. Her older three siblings, for an unknown reasons, do not assist her with providing food or support for their mother. She has been caring for her mother for a period of 1 year 6 months. She has young children who she is solely responsible for and who live with her and her mother in the same household.

Family Caregiver 8:

Is a 62 year old female from a rural area who never attended school. She is caring for her 28 year old daughter who was diagnosed with cancer of the skin in 2017. Since diagnosis, her daughter received treatment (chemotherapy) in a South African Hospital over a period of 2 years with the assistance of Eswatini government's Phalala Fund. In the 2 years, she would go away for 2 months and come back homes. Her treatment was not complete after the 2 years and upon return she was told that Phalala Fund could no longer afford to pay for her treatment thus her treatment stopped.

The daughter used to be a domestic worker but had to stop working due to her illness. The 62 year old mother is also unemployed but rears pigs and plants crop like maize, groundnuts and vegetables like sweet potatoes. She also receives an elderly grant of 1500 emalangeni (the equivalent of SA R 1500) every 3 months which helps to meet some of their basic financial needs.

The mother has been caring for her daughter for 3 years and the daughter lives with her 3 children and has no husband.

Family Caregiver 9:

Is a 32 year old daughter from a peri-urban area who never completed high school but studied up to grade 8. She was caring for her 53 year old mother who was diagnosed with cancer of the breast in 2012 but luckily had a mastectomy. However, in 2015 she received a cervical cancer diagnosis and had to receive treatment (chemotherapy) in a South African hospital for a period of 3 months in 2016 with the assistance of Eswatini government's Phalala Fund. After the 3 months, she had to stop treatment as it was reported that the funds were now insufficient to send people to South Africa for treatment.

The daughter was employed in South Africa as a domestic worker but had to stop working and come back home to look after her mother. Her mother was unemployed but would collect cans for recycling and when possible would assist with domestic work like laundry in homesteads that needed help within the community.

She lost her mother in March 2020 after having cared for her for a period of 6 years. This caregiver has 5 siblings, some of whom she also had to take care of whilst looking after her mother.

Family Caregiver 10:

Is a 79 year old man from a peri-urban area who attained tertiary education. He was caring for his 69 year old wife who was diagnosed with cervical cancer in 2009. Since diagnosis, the wife received treatment (chemotherapy) for 1 month in a South African hospital with the assistance of

Eswatini government’s Phalala Fund. After the 1 month she had to stop treatment and was never given the reason and sadly in 2016, her husband also received a diagnosis of prostate cancer. The husband as the caregiver had to receive his own treatment (surgery) while having to continue to look after his wife.

The husband is a retiree who was working at a timber company and still receives a pension from the company. The 79 year old husband has children who support him financially.

He lost his wife in December 2019 after having cared for her for a period of 11 years. Together he and his wife have 4 children.

4.4 Needs and Challenges of Family Caregivers

Given that interviews conducted in this study were semi-structured and reflected the objectives of the research, the key findings will be presented in relation to these objectives.

It cannot be ignored, however, that the field work for this study took place during the COVID-19 pandemic, the first cases of which were reported in March 2020 in Eswatini. The pandemic introduced additional concerns for the family caregivers. For example, family caregivers were concerned about having to make a hospital visit. One caregiver shared the following:

> “… I get scared when we have to go to hospital (now), I worry that we might contract the virus” (Caregiver 4, Wife, 48 years).

Despite the above-mentioned fears, the caregiver was quick to point out that together with her husband (i.e. the patient), they used precautions like wearing a mask and maintaining a social distance from others at the hospital. It was reassuring to note that all caregivers were familiar with the safety measures they needed to take in preventing the spread of the COVID-19 virus, but were concerned about the end of the COVID 19 pandemic and wondered if they would have to wear masks in public places for the rest of their lives.

4.4.1 The Needs of Family Caregivers

Family caregivers highlighted a number of needs that they experienced when caring for their family member with cancer: from the time of their diagnosis through to their passing. These included a need for being better informed and prepared for their role as caregiver, the need for emotional support as primary caregiver, the need for assistance from rural health motivators in the care of the sick family member, the need for some encouragement as primary caregiver, the need for transport for the regular hospital visits they made with their sick family member and basic needs, such as food for themselves and their family.

Family caregivers reported feeling wholly unprepared for their home-based care role – largely due to lack of information they received (or did not recall receiving) when assuming the role of primary caregiver. At the same time, they all shared how important it would have been to have received some form of emotional support in the form of counselling whilst they were caring for their sick family member.

In most instances the interviewees were not only responsible for caring for the patient but were also the one that was responsible for managing the household – and in seven instances, responsible for bringing up their own children and/or their grandchildren. Their responsibilities as a home-based carer, coupled with these other responsibilities – and in circumstances of financial insecurity, placed a heavy emotional burden on the interviewees. The provision of counselling support to the carers could undoubtedly have lightened their emotional load. The next section describes in greater details these two priority needs as they were highlighted by the family caregivers, organized into sub-themes.

4.4.1.1 Preparedness of caregivers for caregiving

Eight of the ten family caregivers reported feeling unprepared for their role as primary caregiver: not only at the outset – but also, despite gaining practical experience, as they continued to care for their sick family member. Most of the interviewees shared that they never received information related to providing palliative care from healthcare workers in hospitals where they received the diagnosis of their sick family member. In addition, two caregivers (Caregiver 6, Mother, 67 years and Caregiver 7, Daughter, 27 years) reported not having clear information on the nature of the cancer that their family members were suffering from. They specifically shared their concern about not knowing the type of cancer their family member had, the stage of their illness and their prognosis. One caregiver (Caregiver 6, Mother, 67 years) had a very sad and disappointed expression on her face as she shared how she lost a son whom she believed would get better and return to work. This caregiver, who lost her son 3 months prior to the interview, shared the following:

> "I did not know the extent of his illness, I just thought his condition would improve. He never gave us the impression that he would pass on and I believed he would get better until the time he passed away" (Caregiver 6, Mother, 67 years).

All of the 10 family caregivers expressed significant concern about their lack of knowledge about the correct way in which to care for their family member – such as knowing how to manage symptoms at home, and what the proper techniques for moving their sick family member was, especially those who were bedridden. They all reported with concern that they have never cared for a sick family member before and such an experience was a big adjustment for them. As a result, they mentioned offering care in a way which seemed appropriate to them – although they were not certain if what they were doing was correct. Their lack of confidence in relation to whether they were correct or not was often shared with some sadness as they suggested that they felt they were letting their sick family member down by not offering them the best possible care. A daughter who was looking after her mother with cancer of the rectum had this to share:

> "I was not given information on how to care for my mother. I offer care in my own way since I do not have information. I do not know if I am doing it ok but it is the best I can do under the circumstances..." (Caregiver 7, Daughter, 27 years).

In a similar vein, an elderly male caregiver, who lost his wife 6 months prior to the interview shared:

> "I offered care as I saw fit since I did not have knowledge on caring. It was painful since my wife would cry when I was assisting her and I did not know what to do, she was in a lot of pain as she had bed sores. It is still painful to me when I recall that experience..." (Caregiver 10, Husband, 79 years).

All caregivers expressed a desire to offer the best nursing care for their family member despite their lack of formal training. As reported above, the interviewee (Caregiver 10, Husband, 79 years) had difficulty in caring for his wife towards the end of her life when her condition worsened.

Having expressed the desire to offer quality care – many of the caregivers recommended that the Ministry of Health provide family caregivers with greater support from, for example, doctors and nurses who could make home visits to monitor the health of their sick family member at home. They felt that given they were not always able to manage the patient's symptoms within the home environment, they felt that they could benefit from a monthly home visit from a professional health care worker. A male caregiver who lost his wife one month prior to the interview shared the following:

> "I fear this cancer, after what my wife went through. It would be helpful if the Ministry of Health would send a doctor once a month to examine a sick family member at home. In this way I am sure as a relative I would also be screened for cancer, I am really scared of this disease" (Caregiver 2, Husband, 43 years).

Similarly, a female caregiver who lost her son three months prior to the interview had this to say:

> "The ministry should allow nurses to visit our sick family member at home, or better yet, have mobile clinics to assist caregivers looking after their sick family members. In this way, services would be closer to communities and accessible to us. I could not afford to take my son to hospital for monitoring and it was painful as I felt I was not doing everything I should for him" (Caregiver 6, Mother, 67 years).

In one instance, a caregiver (Caregiver 7, Daughter, 27 years) who was lacking information reported that she feared asking for information from health care workers in Hospital. She had this to share:

> "No I did not ask for information, you know healthcare workers, they can be very rude and I was scared even to ask…" (Caregiver 7, Daughter, 27 years).

The two caregivers (i.e. Caregiver 2, Husband, 43 years and Caregiver 9, Daughter, 32 years) that did report having received information to support them in their caring role reported that they were provided with information related to personal protection like how to use gloves when offering care and what they ought to do in terms of providing proper nutrition for their family member at home.

4.4.1.2 Emotional support for family caregivers

Apart from requiring more information about their family member's illness and some basic skills about how to provide home-based palliative care, family caregivers also highlighted another critical need: the need for emotional support. Four family caregivers (Caregiver 1, Mother, 70 years; Caregiver 4, Wife, 48 years; Caregiver 5, Daughter, 43 years and Caregiver 7, Daughter, 27 years) specifically reported feeling alone in the context of providing palliative care to their sick family member. Words like "lonely" and "abandoned" were used in the interviews as these four family caregivers expressed their feelings of being by themselves and unable to talk with anyone about their caregiving experience. A daughter, taking care of her mother shared sorrowfully:

> "I know I have to take care of my mom till she dies. I feel abandoned in this situation with no one to share my thoughts and feelings. I cannot tell my mom about my worries and she is the only other adult in this house" (Caregiver 5, Daughter, 43 years).

One interviewee (Caregiver 4, Wife, 48 years) reported that the experience of caring is not one that can be easily shared with others in the household – especially if the other members are children who, she felt, were too young to understand the situation. She emphasized how helpful it would have been to access counselling and encouragement from health care workers in her scenario. The interviewee had this to say:

> "I have no one here at home to talk to, even though I would love to share my experience or my difficulty with someone. I need counselling and it would be nice if healthcare workers would encourage me so that I stay positive and motivated" (Caregiver 4, Wife, 48 years).

Among the other six family caregivers who did not explicitly share that they felt isolated or alone in their role as the caregiver, two caregivers (Caregiver 3, Mother, 60 years and Caregiver 8, Mother, 62 years) reported relying on God and praying for strength to offer care for their family member. One interviewee had this to share:

> "I am a prayer women, this gives me strength, and otherwise I would not be able to bear the condition of my son" (Caregiver 3, Mother, 60 years).

Likewise, the other interviewee shared:

> "I accepted my daughter's condition and prayed to God for guidance, He is my source of strength" (Caregiver 8, Mother, 62 years).

Most caregivers reported experiencing a range of emotions associated with their caregiver role - making the need for emotional support understandable. For example, they reported high levels of anxiety and considerable distress at the worsening condition of their sick family member. One caregiver (Caregiver 1, Mother, 70 years) mentioned that she was worried at seeing the condition of her family member deteriorate. She had the following to share, with great sorrow in her voice:

> "I felt powerless as I had tried everything. My daughter was not getting better and she had been sick for a very long time. I was worried about her losing weight and looking very thin" (Caregiver 1, Mother, 70 years).

Some caregivers (Caregiver 4, Wife, 48 years and Caregiver 7, Daughter, 27 years) reported feeling unappreciated and overwhelmed – so much so that one interviewee even considered walking away from the situation. Discouraging comments from the sick family member of course exacerbated such feelings. As the interviewee shared:

> "My husband shouts at me sometimes and this makes me very angry because I am doing all that I can to make sure that he is well taken care of. I feel so much unappreciated and this makes me to think that I should just pack and leave. However, I know that he cannot survive without me. I know that he gets like this when he runs out of his pain medication so I do understand" (Caregiver 4, Wife, 48 years).

Apart from feeling unappreciated and overwhelmed, anger was another emotion that family caregivers reported. Two caregivers (Caregiver 2, Husband, 43 years and Caregiver 3, Mother, 60 years) specifically reported feeling extremely angry and powerless as a result of interference by in-laws in the care of the sick family member. One interviewee had this to share:

> "When my wife was diagnosed with cancer, her relatives took over and that made me angry. They made her go to traditional healers, prayer people and she was (having to) drink all sort of traditional medicine. Her relatives would not allow me to take her to hospital for treatment and I was stressed by their behaviour. I could not believe that they

> thought what they were doing would cure the cancer. I tried telling them that cancer cannot be treated the way they were doing but no one was willing to listen for some time and I felt helpless…" (Caregiver 2, Husband, 43 years).

As can be expected, the critical needs that the caregivers expressed during the course of the interviews are intertwined with the challenges they experienced. These are described in the next section of this chapter.

4.4.2 The Challenges of Family Caregivers

Further challenges shared with the interviewer in the course of the interviews included having to face a sense of uncertainty about their own future – particularly in the face of having to manage the deteriorating health of their family member – and in five cases: the death of their family member. Other challenges included lacking sufficient time to manage their own health as primary caregivers (given the many caring activities and other household activities they had to take care of) and having minimal or no financial support to be able to provide the best quality medical or nursing care for their sick and/or dying family member. Not being able to access familial support from the relatives of those that they were caring for was another challenge that was raised. Caregivers also talked about the challenge of not being able to rest themselves – and have some time to recuperate. Lastly, another challenge they faced was not being able to adequately engage with health care workers about the care and treatment that was being planned and offered to their sick family member. The next section of this report describes these in greater detail, organized into several sub-themes.

4.4.2.1 The challenge of an uncertain future after the death of the sick family member

A number of caregivers reported feeling uncertain about a future without the family member. Specifically reporting this challenge were some family caregivers (Caregiver 5, Daughter, 53 years; Caregiver 7, Daughter, 27 years and Caregiver 8, Mother, 62 years) who were still caring for their family member. The word "sudden" was often used to describe the anticipated death of their family member and it was common for this group of carers to report living in constant fear of the time when their family member would pass on, and they would be left alone. One caregiver (Caregiver 5, Daughter, 43 years) reported with an expression of deep concern on her face – the worry of losing the company of her mother who she was so used to. She had this to share:

> "I prayed so much to God, asking for guidance since I feared that my mother would die suddenly and such thoughts make me feel so much pain. I was afraid that she would leave me alone and yet I am so used to her company since we (have been) living together in this house …" (Caregiver 5, Daughter, 43 years).

One caregiver (Caregiver 10, Husband, 79 years) who had lost his wife 6 months ago, recalled vividly his feelings of sadness towards the end of his wife's life. The sad memories that he was left with after she passed away were clearly still apparent as he narrated his feelings of hopelessness about a future without his wife. He had this to share:

> "I feared being left alone. I wanted to die first, before my wife. When my wife was sick, I thought to myself that if I could get someone who would give me the opportunity to trade

> places with her and die instead of her, so that she could live and be better" (Caregiver 10, Husband, 79 years).

4.4.2.2 The challenge of managing their own health as caregivers

Caring is not only emotionally challenging but physically challenging – it takes a toll on the carer. On a typical day, caregivers reported having to bath the sick family member twice a day, some had to turn their bedridden sick family member to a comfortable position every 2 hours and others reported having to assist their sick family member to the toilet. Caregivers often reported on the physical strain that they experienced when navigating these caregiving duties. One caregiver had this to share:

> "Turning my daughter is a difficult task when you are old like me. Every time I turn my daughter, my body aches all over – (it's) as if I have been lifting heavy stones…" (Caregiver 8, Mother, 62 years).

A male caregiver who lost his wife one month prior to the interview shared:

> "I could not get enough sleep when caring for my wife since I had to wake up every now and then to take her to the toilet, and sometimes give her medication as the pain would wake her up in the middle of the night. The next day I would wake up feeling very fatigued and this affected my work as I would fail to do anything (the next day)" (Caregiver 2, Husband, 43 years).

In addition to the practical tasks they did as the primary caregiver, most caregivers reported also having to manage a set of household activities like cooking for the sick family member, doing laundry for the household, keeping the house clean and for some, sweeping the yard. One interviewee had this to share:

> "…you know, sick people have a lot of laundry and doing laundry takes up a lot of my time…this is too much work for me on top of caring for my daughter" (Caregiver 1, Mother, 70 years).

The various activities associated with caregiving and managing the household left little or no time for caregivers to look after their own health. This was worrisome for many, especially those (Caregiver 3, Mother, 60 years and Caregiver 8, Mother, 62 years) who had a pre-existing condition i.e. hypertension. There appeared to be insufficient time to prioritize their own monthly hospital visits for check-ups and refills of medication. Although one interviewee was rather vague in describing what she did once her medication ran out, the concern on her face was very visible in the interview. She had this to share:

> "…I have hypertension but I am not able to go to the hospital. I do not have time to look after my own health as I have to do everything around the house and besides, I cannot leave my son alone here at home in his condition…" (Caregiver 3, Mother, 60 years).

Despite expressing extreme concern for their own health, caregivers were quick to point out that the health of their sick family member takes priority. They seemed genuinely satisfied about putting their family member first.

4.4.2.3 The challenge of having minimal or no financial support

Nine family caregivers reported experiencing financial challenges whilst caring for their family member with cancer. From the point of diagnosis to the period in which the interview was conducted, 7 of the 10 caregivers remained unemployed, with two (i.e. Caregiver 7, Daughter, 27 years and Caregiver 9, Daughter, 32 years) having to specifically stop working to provide care to their sick family member. A daughter who lost her mother 4 months prior to the interview had this to share:

> "I was employed in South Africa and since my mother got sick, I had to take time off every now and then until it was no longer possible. I eventually had to stop working and look after my mother and some of my younger siblings. This was difficult as there was no source of income…" (Caregiver 9, Daughter, 32 years).

Likewise, another interviewee stated:

> "When my mother got sick, I decided to stop working since none of my siblings was willing to take the responsibility for caring for our mother. It is hard on me since I have my own children to take care of…" (Caregiver 7, Daughter, 27 years).

Some of the Caregivers reported trying to keep engaged in income generating projects in an attempt to meet their financial needs. For example, some family caregivers (Caregiver 2, Husband, 43 years; Caregiver 6, Mother, 67 years and Caregiver 8, Mother, 62 years) reported feelings of hope about doing a bit of farming to provide food for their families. An elderly grant of 1500 emalangeni (equivalent to SA R 1500) provided financial support for most caregivers interviewed. One interviewee had this to share:

> "My daughter lost her job as a domestic worker when she got sick and she was the bread winner. The elderly grant of 1500 emalangeni that I receive every three months is not

> enough to support us. I decided to rear pigs and plant crops like maize, groundnuts and vegetables like sweet potatoes. It is not much but it helps a lot…" (Caregiver 8, Mother, 62 years).

In a similar vein, another interviewee shared:

> "I have land for farming but due to my age I am not able to farm. I used to make hand-crafted mats to sell but had to stop since I was not making any money out of it…" (Caregiver 1, Mother, 70 years).

Some caregivers, however, (Caregiver 1, Mother, 70 years; Caregiver 6, Mother, 67 years and Caregiver 7, Daughter, 27 years) reported not being entirely alone in having to face the financial difficulties given they received some financial support from community members like neighbours, politicians and friends. An elderly female caregiver had this to share:

> "My neighbour assists sometimes with transport to send my son to hospital and he offers this as a donation as I do not have to pay him…" (Caregiver 6, Mother, 67 years).

In a similar vein, another shared:

> "My daughter's friends send her money sometimes for hospital visits. At other times her friends would hire transport to fetch her when she has to go to hospital…" (Caregiver 1, Mother, 70 years).

Caregivers reported surviving on small amounts of money from day to day which were often not sufficient to meet their basic financial needs. The consequences of such financial hardship were reported by many caregivers, for example, this caregiver shared with great sorrow:

> "I know that my son needs to go to hospital but due to lack of money, he cannot go there. I look at him trying to move around the home and it is with great difficulty and pain. I need to hire transport for him and that would cost 300 emalangeni to and fro and I cannot afford (that)" (Caregiver 3, Mother, 60 years).

4.4.2.3 The challenge of not being able to access familial support from relatives

Another challenge reported by many of the caregivers was the lack of support from family members in supporting the care of the sick family member. Some caregivers (Caregiver 1, Mother, 70 years old; Caregiver 7, Daughter, 27 years old; Caregiver 8, Mother, 62 years old and Caregiver 9, Daughter, 32 years) described with anger the difficulty of having to care for a family member on their own. A female caregiver who lost her daughter one month prior to the interview stated:

> "I had no support from my relatives in caring for my daughter until she died. Even her husband did not want to be involved in any way and I had to make do on my own. I am glad that I managed to bury my daughter in dignity despite such lack of support from those close to her" (Caregiver 1, Mother, 70 years).

Another interviewee had this to share:

> "When my mother got sick…no one was willing to take responsibility for caring for my mother. It is hard for me since I have kids (of my own) to take care of. None of my siblings wanted to be involved…" (Caregiver 7, Daughter, 27 years).

Caregivers narrated how relatives took a back seat on a matter that required the family to come together to offer assistance. One caregiver (Caregiver 9, Daughter, 32 years) stressed how relatives could definitely afford to assist but had decided not to. She had this to share:

> "I was alone in caring for my mother and my relatives did not offer any support. I have aunts and uncles who are doing well in life and I do not understand why they failed to support me at a time I needed family support (the) most" (Caregiver 9, Daughter, 32 years).

Echoing the lack of financial support provided by family members and relatives of those who were sick, some caregivers pointed out that that they had received very little practical support in relation to actually caring for their sick relative. In many of these cases they highlighted how they had in fact received most of their support from friends and neighbours. This came in the form of food parcels, assisting with laundry and making visits to check on the sick family member and offering some prayer. A mother caring for her daughter had this to share:

> "Neighbours visit my daughter most of the time just to check on her. They even offer prayers and this is good for her spiritual well-being. Sometimes they come with food parcels and this makes me feel at ease knowing I have some support in caring for my daughter" (Caregiver 8, Mother, 62 years).

However, not all family caregivers were without familial help: five caregivers reported receiving support from relatives like children and siblings. They expressed relief at having relatives at such a challenging time in their life. One caregiver (Caregiver 10, Husband, 79 years) mentioned that he cannot imagine how he could have survived without the support from his children. He had this to share:

> "…my children are very supportive. I have a daughter-in-law who brings food every morning and does her bit before returning to her homestead. I did not have to do everything on my own…." (Caregiver 10, Husband, 79 years).

4.4.2.4 The challenge of not being able to adequately engage with health care workers within health care system

Most caregivers reported frustrations with the health care system. As mentioned in section 4.4.1.1 some caregivers (Caregiver 6, Mother, 67 years and Caregiver 7, Daughter, 27 years) reported not being provided with clear information on the diagnosis and prognosis of their family member and this made them unprepared for caregiving. Two caregivers (Caregiver 5, Daughter, 43 years and Caregiver 7, Daughter, 27 years) reported that their family members never received chemotherapy at the hospital of diagnosis. A daughter caring for her mother had this to share:

> "My mother never received treatment since diagnosis and I do not know the reason. I have heard that others with the same condition receive chemotherapy but my mother has not received it. I am left with questions…" (Caregiver 5, Daughter, 43 years).

Similarly, another caregiver had this to share:

> "I do not remember my mother receiving any form of treatment. All I remember is that she was done a biopsy and she was told that she would be sent to South Africa for further treatment. However, that never happened as we were told that the Government is owing the South Africa Hospital where my mother had to go. Since we could not afford to take

> her, we have been waiting ever since, for Government to tell us that the debt has been cleared and we can go to the hospital" (Caregiver 7, Daughter, 27 years).

The issue of the Eswatini government owing money to cover the cost of care in South African hospitals (where some cancer patients receive treatment) was reported by three caregivers (Caregiver 4, Wife, 48 years; Caregiver 8, Mother, 62 years and Caregiver 10, Husband, 70 years) – all of whom had sick family members that never completed their treatment as a result of this debt. Expressions of anger and frustrations were visible on the faces of caregivers as they reported how they were left in the dark on what to do in relation to the care of their family member during this time and whilst waiting to go back to South Africa for treatment through Phalala Fund. One caregiver had this to share:

> "My daughter went once to South Africa and stayed for 2 months. When it was time for her to go back, she was told that Phalala Fund does not have money and if she wishes to return, then she can pay for herself…" (Caregiver 8, Mother, 62 years).

The unavailability of pain medication like morphine at nearest health centres was reported as an added frustration by family caregivers. Most caregivers reported having to travel to far away hospitals to get pain medication. In light of their financial struggles (reported in section 4.4.2.3) this made the lack of access to basic pain medication even more of a challenge to manage. One interviewee had this to share:

> "…most of the time the facility does not have the pain medication that my husband requires thus I have to go to a far hospital with my husband just to get medication" (Caregiver 4, Wife, 48 years).

In similar vein, another interviewee shared:

> "I had to move from hospital to hospital seeking morphine for my sick mother. I do not understand why such medications is not available to us" (Caregiver 7, Daughter, 27 years).

Challenges that were experienced with the health care system were reported by caregivers as also hindering their ability to provide quality care to their sick family member within the home environment. The lack of home-based care commodities, like gloves and adult diapers, was reported by most caregivers as another frustrating challenge. An elderly mother who lost her son 3 months prior to the interview had this to share:

> "I was not given any personal protective equipment like gloves yet my son had a wound which needed to be cleaned within the home environment. I was never told where to get such commodities and helping keep my son's wound clean was difficult…" (Caregiver 6, Mother, 67 years).

Sadly, most caregivers reported not having visited the local clinic to seek assistance with the care of their family member. Some caregivers (Caregiver 7, Daughter, 27 years and Caregiver 10, Husband, 70 years) suggested that their lack of trust or faith in their local community clinic was one of the reasons they did not seek assistance from them. One interviewee had this to share:

> "To be honest, I have never visited the nearest clinic, so I do not receive support from them. They do not know my mother's situation at all and I do not think they are in a position to assist me in any way" (Caregiver 7, Daughter, 27 years).

Having shared the numerous challenges they experienced with the local health facilities, all caregivers requested that the Ministry of Health makes pain medication and commodities for home-based care (like gloves and adult diapers) readily available at community clinics. A female caregiver caring for her daughter stated:

> "The Ministry of Health once provided commodities like adult diapers when HIV infections were high and this was very helpful within communities. There were centres within the community where relatives would fetch different needed commodities and it would be helpful if the Ministry would make such provisions once more" (Caregiver 8, Mother, 62 years).

In a similar vein, another interviewee shared:

> "I need pain medication to be available in a close-by health facility. I do not have money to travel to very far hospitals just to get such medication. The Ministry does not seem to consider people living with cancer when making medication available to facilities" (Caregiver 4, Wife, 48 years).

4.5 Summary of Findings

This chapter presented the results and narratives of the study findings. As described in this chapter, the 10 family caregivers that were interviewed identified a number of unmet needs they experienced as home-based caregivers. The priority ones being a need for better information and preparation in anticipation of their role as a caregiver and that they receive some form of counselling support themselves to assist them to emotionally manage as the primary caregiver.

There were a number of other challenges which they also identified as impeding the quality of care that they could – and would like to – ensure that their sick family member received at home.

The challenges that they identified made this difficult to provide. For example, caregivers shared how they were faced with a sense of uncertainty about their own future after the death of the sick family member and witnessing the deteriorating health of their family member made their caregiving responsibility very hard to manage on a personal level.

Lacking the time to manage their own health was another challenge that was highlighted. This lack of time to care for themselves (the ‘Care for the Carer’) was a result of them having to fulfill multiple roles in the home simultaneously: primary caregiver of the patient, adult responsible for managing the household, guardian of the children.

Many of the Caregivers had insufficient finances and received little financial (and in some cases, familial) support which they felt had significant consequence for the care of their family member. Much needed hospital visits were therefore not possible for some. In some cases, they had to carry the burden of caregiving alone.

Caregiving was also made difficult by health care workers within the health care system who did not communicate well with the caregivers. It appeared that they (health care workers) did not provide sufficient guidance about the nature of the disease that their (caregiver) sick family member was living with, the treatment plan that had been developed for their family member and their prognosis. Coupled with this lack of communication was the additional challenge that local health facilities were frequently lacking essential pain medication and basic home-based commodities (such as gloves and adult diapers) which are needed to provide quality care in the home environment.

In the next chapter, the researcher will discuss study findings.

CHAPTER 5: DISCUSSION

5.1 Introduction

This chapter discusses the importance of the study findings. The objective of the study was to gain an understanding of the needs and challenges perceived and experienced by family caregivers in the Hhohho Region of Eswatini in providing palliative care for a family member with cancer. In addition, the study aimed to explore the kind of support family caregivers would find most beneficial to receive from local health professionals within the Ministry of Health. Findings from this study will be examined in relation to existing literature with the hope of gaining a greater understanding of the implications of this study for future practice pertaining to the support required for family members providing home based palliative care in the region.

What is apparent from the study findings is that the Ministry of Health is *not* providing sufficient support to family caregivers. Whilst a number of the needs and challenges of family caregivers providing palliative care within the home is generally known in the literature, this study highlights how important it is to consider the *multiple* responsibilities and caring roles that the carers hold and have to assume. This is particularly significant for the Ministry of Health to take cognizance of given the poor socio-economic situation the palliative care patients and their family carers (and, of course, their households) find themselves in. In all cases, those interviewed described a palliative care setting which was characterized by considerable resource constraints and financial and emotional vulnerability.

Family caregivers are faced with numerous needs when providing palliative care. Those that appeared to be most critical are discussed in the next section of this chapter.

5.2 The Needs of Family Caregivers

5.2.1 Preparedness of caregivers for caregiving

As highlighted in the literature review, the lack of preparedness on the part of a household member to provide palliative care to their family member is well known. Some authors (Harding *et al*. 2012 and Mazanec *et al*. 2018) found that caregivers lacked the necessary skills to assume the comprehensive scope of clinical caregiving tasks. These included, for example, being able to manage symptom control and manage the various medications (Henriksson & Stedt, 2013). Similar findings from Henriksson & Stedt (2013) were revealed in this study as caregivers lacked clear information on the specific illness of their family member, the prognosis of sick family member, and how to manage symptoms at home and correctly move their bedridden family member.

Lacking the necessary skills and information obviously influences the way in which family caregivers provide care. In most cases the study participants described how they "do what they can" and thus offer care to the best of their knowledge and in a way that seems best to them. This is described in the study in the case of a daughter caring for her mother (Caregiver 7) who, totally unsure of what the most appropriate and best care practice is in this situation, shared how she "… offer[s] care in my own way since I do not have information".

This narrative illustrates feelings of helplessness on the part of the caregiver - which is often accompanied by a sense of fear, anxiety and a lack of confidence about caregiving abilities (Kehl *et al*., 2015). Being prepared for taking on such a caregiving role is an important topic that health care workers should discuss with family members when they are briefing them about what they can anticipate and need to plan for in terms of caring for their family in the future. Preparedness is also an important factor contributing to the health and wellbeing of family caregivers (Holm *et al.*, 2014).

5.2.2 Emotional support for family caregivers

In addition to the caregiver's experience of being unprepared for their role as carer, the study also has been able to demonstrate the great need to provide emotional support to family caregivers, echoing the findings of a study conducted in Ghana with 23 caregivers who described their experience of being a carer as a feeling of being alone in the middle of the sea (Salifu, Almack & Caswell, 2018). Caregivers feeling "alone and abandoned" was specifically highlighted by four caregivers in this study. The burden of caregiving their sick family member was something they had to hold and bear alone – despite their being other members of the household present. This is understandable given that all caregivers live with and take care of children in their households. This is pertinently described in the case of a wife (Caregiver 4) caring for her husband "longing for counselling and encouragement from health care workers".

Similar findings of caregivers needing emotional support from healthcare workers in the form of direct expressions of empathy, offering encouragement and enquiring or expressing concern for the caregiver's wellbeing were reported in a study conducted in the United States by LaValley (2017). Interestingly this study demonstrated that when emotional support for the carer is lacking, some caregivers turn to religion for strength. Although this type of support is not discussed in most literature, any form of support perceived to be helpful for the caregivers ought to be acknowledged. As Lessard, Leclerk & Mongeau (2014) note, caregivers cope better if they sense there is adequate support for them during the caring period.

As described in Chapter 4, caregivers also experience a lot of different emotions which can also determine how well they are able to manage in the caregiving situation. The deteriorating condition of a sick family member will likely raise the anxiety and distress in caregivers, - as was described by a mother (Caregiver 1) who was left feeling powerless at witnessing the deteriorating state of her daughter's health as a result of lung cancer – despite doing everything in her power to see her improve. She shared: "I have tried everything and there is no change in illness". Previous research also reports such findings – for example, a study conducted in the United States by Mazanec *et al*. (2018) found that the poor health of a family member was associated with anxiety and distress on the part of the family caregiver.

The burdensome nature of caregiving can leave family caregivers feeling overwhelmed. Depression observed in patients receiving palliative care in a study conducted in the United States by (Ferrell & Kravitz, 2017) makes them harsh towards caregivers which in turns leads to caregivers feeling unappreciated. In the narratives of two caregivers in this study (Caregiver 4 and Caregiver 7), they reported "being shouted at" by the sick family member and this made them (the caregivers) feel unappreciated. Such feelings can also be exacerbated by the interference of relatives in the care choices for the sick family member. This was illustrated in this study in the case of a male caregiver (Caregiver 2) who struggled to get immediate medical help for his wife because her relatives insisted, she be taken to a traditional healer. In Eswatini, caregivers and patients are free to choose the approach or type of care they prefer and some patients obviously opt for traditional or indigenous medicine. This is not always the most efficacious choice as could be seen in the above case and that of the patient with cancer of the penis (Caregiver 3) who opted for the traditional route which then resulted in further trauma.

Needs of caregivers are connected to the challenges they experience when providing palliative care. The next section discusses the challenges of family caregivers in greater detail.

5.3 The Challenges of Family Caregivers

5.3.1 The challenge of an uncertain future after the death of the sick family member

Previous studies reinforce the fact that family caregivers fear life after the death of a family member. This was observed in studies conducted by Harding *et al*., (2012) and Salifu, Almack & Caswell (2018) in the United Kingdom and Ghana respectively, and also observed in this study where family caregivers expressed a fear of being alone after their sick family member passes away. This is described in the study in the case of daughter caring for her mother (Caregiver 5), who was afraid of "losing the company" of a mother she is so used to.

In addition, Harding *et al*. (2012) notes that the fear of losing the patient for some caregivers is common amongst those who are financially depended on the family member. Planning a future without the backing of the dying family member represents such an uncertain future for some family caregivers. This scenario was best illustrated in this study by Caregiver 6 who lost her son - the family bread winner - and she was left in a dire financial situation. She described her situation in this manner "…I do not have money for most basic needs…my neighbour assists sometimes with transport to send my son to hospital and offers this as a donation as I do not have to pay him…"

It appears that stressing over an uncertain future is associated with feelings of hopelessness (Ullrich *et al*., 2017) – feelings which do not subside once a family member dies but are often carried forward into the daily life to the caregiver.

The death of the sick family member (i.e. the patient) understandably brings with it a significant experience of loss for the family caregivers - who are now only left with the memories of the past. As Caregiver 10, an elderly caregiver recalled "I feared being left alone. I wanted to die first, before my wife. When my wife was sick, I thought to myself that if I could get someone who would give me the opportunity to trade places with her and die instead of her, so that she could live and be better". The experience of death – and particularly the death of a close family member, coupled with the experience of being the primary caregiver would naturally suggest that some form of counselling would be in order. It is clear from this study that caregivers did not receive much needed counselling to help ease their pain after the loss of their family member. Recalling painful past experiences was obviously still painful for family caregivers.

5.3.2 The challenge of managing their own health as caregivers

In terms of the health of the family caregiver, this study demonstrates that caregiving activities have a noticeable impact on the health of caregivers. In one case, Caregiver 8 experienced body pains which felt like "she had been lifting heavy stones", after turning the bedridden family member. Such findings echo the findings of a study by Gysels *et al*. (2017) where caregivers reported having to do strenuous daily tasks which lead to development of body pains (Gysels *et al.*, 2017). A study by Ferrel & Kravitz (2017) which focused on caregivers providing cancer patients with care noted that they developed caregiving-related symptoms and physical well-being decreases as a patient's condition worsens (Ferrell & Kravitz, 2017).

It appears that there is often little time to focus on their own health. As this study has illustrated, family caregivers have a range of additional household activities which add to their tasks as the primary caregiver of the patient. Basic household activities take a lot of a caregiver's time - as was described by a mother (Caregiver 1) in this way "…sick people have a lot of laundry and doing laundry takes up a lot of my time…" leaving her with little or no time for self-care. Stajduhar, Martin & Barwich (2008) in a study conducted in Canada state that family caregivers reported experiencing a lack of control over their everyday lives, have restricted leisure time and disrupted personal routines. This scenario is further compounded by the fact that all caregivers in this study live with children and have to therefore split the demand for care for both children and the sick family member who requires palliative care.

As Ferrell & Kravitz (2017) note a condition like cancer, with symptoms requiring 24 hour/day attention in the palliative care phase inevitably leads to family caregivers neglecting their own health. It was also important to note that two participants in this study (Caregiver 3 and Caregiver 8) reported a pre-existing condition: hypertension. These caregivers reported not making their own hospital visits and this was an illustration of how they overlooked their own health and instead prioritize the health of their sick family member. As Girgis *et al.*, (2013) suggests, caregivers who have chronic illnesses of their own tend to be focused on the patient and their recovery rather than their own well-being.

5.3.3 The challenge of having minimal or no financial support

This study shows that caregivers have financial difficulties due to unemployment as 9 out of 10 caregivers were unemployed in this study. Some caregivers, (Caregiver 7 and Caregiver 9), who were employed before the diagnosis of the patient, had to stop working to attend to the care of a sick family member as the condition deteriorated. This is described in the study in the case of a daughter (Caregiver 9) who had to stop working in South Africa as a domestic worker since "it was no longer possible to take time off" to look after her mother thus she had to return home permanently to care for her mother with cervical cancer. As a result of cancer care, caregivers lose wages, consequent to unemployment and reduced hours of work (Ferrell & Kravitz, 2017).

Being unemployed necessitates that the caregivers try to engage in income generating projects. This study illustrates that some caregivers ventured into farming projects to support their families. It can be recalled that one participant in the study rears pigs and farms crops like maize, groundnuts and vegetables like sweet potatoes. Farming appeared to lessen the financial strain in some of the participant's households but for the majority of the caregivers (3 of the 10 in this study), they depend solely on an elderly grant of 1500 Emalangeni (the equivalent of SA R1500) every 3 months. Such a small income means that caregivers have a challenge in meeting basic and health care needs of patients, for example, the need to transport sick family members to hospital.

This study revealed a rare situation where some community members and friends of the sick family member met the financial need of caregivers by providing transport for hospital check-ups needed by sick family members. A mother in this study (Caregiver 1) who received financial support described it in this way: "My daughter's friends send her money sometimes for hospital visits. At other times her friends would hire transport to fetch her when she has to go to hospital…". This suggests that caregivers do not have assistance for transport from hospitals and are left alone to find means of transporting a sick family member to hospital–in light of their financial situation.

5.3.4 The challenge of not being able to access familial support from relatives

Caregiver support is key in provision of palliative care as caregivers who receive support demonstrate improved coping abilities, decreased caregiver depression and reduced risk of physical strain (LaValley, 2017). Half of family caregivers in this study described a lack of support from relatives in providing palliative care for a family member. Caregivers were angry with the situation of having to bear the responsibility of caregiving alone, while relatives "did not want to be involved in any way" in the caregiving situation. This is described in the case of a mother (Caregiver 1) in this way, "I had no support from my relatives in caring for my daughter until she passed away". It is not clear from the accounts of caregivers *why* relatives do not involve themselves in the care of a sick family member. It was also beyond the scope of this study to explore such family dynamics.

In this study, it is clear that caregivers do not have the same experience in terms of support from relatives, as the other half of caregivers did receive support from relatives like children and siblings. This suggests that the issue of support from relatives is not determined by factors like the condition of a sick family member but it solely rests on decisions of relatives.

5.3.5 The challenge of not being able to adequately engage with health care workers within the health care system

Caregiver participants in this study expressed considerable difficulty in engaging with health care workers – with all (but 3) having little contact with health care workers at the local clinic. As mentioned in the previous section (Section 5.1), many of the caregivers reported not being given clear information about the type and prognosis of the cancer that their family member had.

It was also reported that two caregivers (Caregiver 5 and Caregiver 7) had family members who never received any treatment, without being provided with any explanation as to why this was the case. This is described in the case of a daughter (Caregiver 7) who was left with questions when her mother was sent home without treatment, "I do not remember my mother receiving any form of treatment…she was told that she would be sent to South Africa for further treatment. However, that never happened…we have been waiting ever since…". Among family members who were initiated on cancer treatment in South Africa, the study revealed that treatment was never completed in sick family members of Caregiver 4, Caregiver 8 and Caregiver 10 as they were told that funds from the Government owned Phalala Fund (explained in section 2.2) were insufficient to send people for treatment to South Africa. Caregivers were left in the dark on how to proceed with care, while waiting for a response from the office of the fund that would give them the *go ahead* in terms of continuing treatment in South Africa.

It is really disturbing that caregivers in this study had to wait at home without follow-up from the relevant office (i.e. Phalala Fund) about treatment of sick family members. This occurred despite the fact that the Ministry of Health does not offer home-based palliative care services (as mentioned in section 1.2). The Ministry of Health (2018) in its palliative care guidelines reports commitment to providing quality palliative care services to all service recipients yet on the ground this is not the case. Caregivers of cancer patients needing palliative care are neglected at home.

In addition to the challenge of poor communication with the health service, caregivers also raised the issue of lacking access to pain medication (i.e. morphine) – from nearest health centres, which according to the Ministry of Health should dispense such medication. This is described in the study in the case of a wife (Caregiver 4), who had to travel with her sick husband to a faraway hospital just to get morphine. Unavailability of medication added sorrow to family caregivers who had to watch family members suffer in pain. The burden of care for family caregivers is worsened by shortage of hospital resources like medication (Gysels *et al*., 2017). Basic commodities like gloves and adult diapers were also not made available for the patients from the local health centres and this led to frustration among family caregivers. Many of the caregivers had no idea where to get needed commodities and this on its own had a negative bearing on caregiving. Unavailability of medication and commodities at health centres is disappointing, given that the Ministry of Health (2018) in its palliative care guidelines reported having prioritized the expansion of palliative care services through the integration of palliative care services at hospital and health centre level and the availability of palliative care medicines and supplies.

It is surprising that cancer caregivers are given the responsibility of providing home-based palliative care when health care facilities do not have the necessary supplies to support provision of care in the home environment. Almost all (9 of the 10) of caregivers reported lacking the following supplies:

1. Morphine

2. Adult diapers

3. Gloves

4. Linen savers

Caregivers need the above supplies in providing care, for example caregivers need gloves when performing care duties like wound dressing, changing diapers and bathing a family member.

Working without gloves increases the risk of HIV transmission between family caregiver and sick family member who are infected. Considering the financial situation of family caregivers, it is not possible for them to purchase commodities in private facilities. However, it is worth noting that an NGO which provides home-based palliative care within the region closed the gap where government has failed.

This NGO provides a number of supportive services that range from monthly home visits, provision of some treatment, to provision of home-based commodities like adult diapers and some form of counselling. The NGO has one health care worker (nurse) within the region, who offers visits on a monthly basis to patients with cancer, mostly. This is not sufficient for family caregivers providing home-based palliative care but it assists to a certain extent. Home-based visits were described by family caregivers as not being frequent according to their needs but understood that due to the size of the region, one nurse cannot meet the demand for service.

The experience of caregivers with local clinics and health centres is evidence of the fact that referrals from hospitals to lower level facilities are not made. Caregivers in this study mentioned not visiting nearest clinics and health centres did not make contact with them (caregivers). This is described in the study in the case of a daughter (Caregiver 7) caring for her mother:

> “To be honest, I have never visited the nearest clinic, so I do not receive support from them. They do not know my mother’s situation at all and I do not think they are in a position to assist me in any way”.

This research has revealed that cancer caregivers are on their own, struggling in isolation to provide home-based palliative care. One would expect given that family caregivers are taking some of the burden of care off the workload of the public health service, the Ministry of Health would offer more support to caregivers - but this is clearly not the case. The concluding chapter which follows, puts forward recommendations for the public health system in Eswatini, to promote increased support for cancer caregivers.

CHAPTER 6: CONCLUSION AND RECOMMENDATIONS

6.1. Conclusion

This study concludes that there are numerous needs and challenges of family caregivers in providing palliative care in the setting of Hhohho Region, Eswatini. Caring for a terminally ill person within the home environment in this context is difficult for caregivers and without question requires continuous support to ease the caregiver burden.

One of the challenges faced by caregivers is their unpreparedness for the task – something which participants in this study were obviously very concerned about. They remarked about the lack of basic information they had had access to and the limited skills and confidence they felt they possessed in caring for their family member. This contributed to their lack of ability to provide the quality of palliative care they so wanted to at home.

Caregiving places a significant emotional burden on the caregiver – especially in this context where the patient is a family member. Many of the family caregivers interviewed lived with their children and their grand-children. They could, of course, not share the emotional burden of caregiving with them – and, for example, share how anxious and distressed they felt. As a result of this burden, caregivers require counselling, support and encouragement from health care workers (LaValley, 2017). However, there appeared to be little or no counselling support that had been made available to those who were interviewed.

Caregivers are also faced with many challenges in their journey of caregiving. One such challenge relates to an uncertain future once a sick family member passes away. Driven by their fear of being alone, they live in constant worry, seeing a future before them that is filled with the loss of their loved one and significant financial difficulties. This was and is particularly common in caregivers who are financially dependent on the dying family member (Harding *et al*., 2012). Despite some of the family caregivers having initiated small income generation projects and others receiving a small grant from the Eswatini government, this was obviously not sufficient to cover the additional demands that had been placed on them whilst caring for the sick family member (e.g. having to take on the care of the *children* of the sick family member). In a number of the narratives, a rather unexpected account emerged of the relatives being noticeably absent in providing their support to the family caregiver. The idea of them "not wanting to be involved in any way", as one participant shared (Caregiver 1), was obviously very painful to observe. The pain of caring on their own and of feeling alone was visible in many of the interviews with caregivers. It was re-assuring to hear accounts of how, in such instances, community support was extended to caregivers who experienced financial challenges – and received little support from their relatives.

Managing their own physical health is another challenge experienced by caregivers. Caregiving activities, compounded with regular household activities result in the caregivers having to manage a significant amount of physical strain. The deteriorating state of the sick family member obviously increases the physical demands placed on the carer with the caregivers often being left with little or no time for self-care and neglecting their own health.

Many of the caregivers also seem to experience a challenge in engaging with and being supported by healthcare workers at their local health facility. Not only were they not provided with sufficient information from the health care workers but they struggled to access the basic home-based care commodities like adult diapers and gloves, and pain medication. In some cases, treatment was not completed as expected with the family caregiver having little explanation as to why that was the case. The study concludes that providing palliative care for a family member with cancer is not a responsibility that should be shouldered by caregivers alone. Palliative care is a basic human right (Open Society Foundations, 2016) and the health service and Ministry of Health in Eswatini now need to think creatively about how they can find more appropriate ways of providing community members – who are upholding such rights – with the essential support that they require.

6.2. Recommendations

Based on the findings, the following key recommendations are made. Whilst such recommendations are not exhaustive, they are offered as a set of initial suggestions as to how local and regional or national health facilities and the Ministry of Health can begin to address (and, hopefully, reduce) some of the challenges experienced by family caregivers when providing palliative care for a cancer patient in the context of the household in Eswatini.

1. Consideration should be given to establishing how home-based care visits from a professional nurse (for example, from the local health clinic) could be incorporated – at appropriate times - into the package of care that is offered by the Ministry of Health to palliative care patients in their homes.

2. The unavailability of essential commodities (such as pain medication and adult diapers, gloves and lines savers) required for home-based, palliative care at local health care facilities requires closer investigation and an assessment and a plan made as to how such supplies can be made more accessible in a *sustained* way to communities caring for palliative care patients.

3. Health care workers working in the Mbabane Government Hospital – the tertiary level hospital where all cancer diagnoses are made in Eswatini, ought to consider ways in which their

communication with the patient and family member at this critical point in time could be strengthened. This might include considering clearer ways of communicating the diagnosis, the prognosis and the proposed treatment plan to the family. Such information could also be then re-inforced by a social worker or counsellor – and a clear plan established about how the family caregiver will access information about how to care for the patient in the home.

4. A simple plan, set of guidelines or a memorandum ought to be developed which outlines how the team at the tertiary level hospital can assist the palliative care patient and their caregiver to link in and access the support of their local primary level health facility once they return home. In this way a stronger continuum of care for the patient could be established given it is clearly absent at present.

5. Practical training programmes for caregivers must be developed by palliative care team within the national hospital to be used in training caregivers at local primary care level, in performing tasks like managing symptoms common in cancer patients at home.

5. Health care workers should use a family-centered approach to care so as to involve caregivers in care plans for family members living with cancer.

6. The availability of counselling for family caregivers should be an essential service that is made available at a local primary care level. Counsellors at primary care level should ensure that cancer caregivers and their sick family member receive counselling and the nursing sister at the same level should ensure such services are offered.

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ANNEXURE 1: Participant information sheet (English)

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E-mail: soph-comm@uwc.ac.za

PARTICIPANT INFORMATION SHEET

Project Title: The perceived needs and challenges of family caregivers in providing palliative care for relatives living with cancer in the Hhohho Region, Kingdom of Eswatini.

What is this study about?

This is a research project being conducted by Mamba Nompumelelo in partial fulfilment of a Master in Public Health Degree I am pursuing at University of Western Cape, South Africa. We are inviting you to participate in this research project because you have been or are a caregiver of a relative who has needed palliative care for cancer. The purpose of this research project is to identify the needs and challenges of family caregivers like yourself in the Hhohho Region.

What will I be asked to do if I agree to participate?

You are requested to participate in an individual interview that will take place within your homestead. The interview will focus on your needs and challenges in providing palliative care and how best you can be supported by the health services. It will be conducted in a quiet room or place to avoid distractions. The interview will last approximately 60 minutes. If you agree to it, I will make an audio recording of the interview and take some notes to assist me with my research.

Would my participation in this study be kept confidential?

As the researcher I will undertake to protect your identity and the nature of your contribution. To ensure anonymity, your name and that of your family members will not be included in collected data. A code will be placed in collected data and only I as the researcher will be able to link the code to your identity. To ensure confidentiality, information will be kept in locked filing cabinets and on password protected computer files. If I write a report or article about this research project, your identity and that of your family members will be protected.

What are the risks of this research?

All human interactions and talking about self or others carry some amount of risks. We will nevertheless minimize such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study.

Where necessary, an appropriate referral will be made to a professional counselor for further assistance or intervention.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help us learn more about the needs and challenges experienced by family caregivers in providing palliative care to relatives living with cancer. We hope that, in the future, the health sector might benefit from this study through the improved understanding of the needs of family caregivers in providing palliative care to relatives living with cancer.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

What if I have questions?

This research is being conducted by Mamba Nompumelelo, a student at the School of Public Health at the University of the Western Cape. If you have any questions about the research study itself, please contact Mamba Nompumelelo at: (Cell +268 76119808) or (Email: melelo2244@gmail.com.)

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Prof U Lehmann

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This research has been approved by the University of the Western Cape's Biomedical Research Ethics Committe.

Biomedical Research Ethics Committee

University of the Western Cape

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ANNEXURE 2: Participant information sheet (Siswati)

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<u>Lifomu lelatisa loyincenye yelucwaningo</u>

Sihloko selucwaningo: Tidzingo nebumatima bebanakekeli bemndeni ekunakeni tihlobo tabo letinamdlavuza emakhaya, esifundzeni saka Hhohho, eveni lase Swatini.

Lungani lucwaningo?

Lolucwaningo lwentiwa ngu Mamba Nompumelelo ekugwaliseni tifundvo takhe esitifikenini se Master of Public Health, eNyuvesi yase Western Cape, kwelase Ningizimu Africa. Siyakumema kutsi ubeyincenye yalolucwaningo ngoba ungumnakekeli noma lowake wanakekela lilunga lemndeni lelidzinge kunakekelwa ekhaya. Umgomo walolucwaningo kubuka tidzingo nebumatima bebanakekeli bemndeni esifundzeni saka Hhohho.

Ngitocelwa kutsi ngenteni uma ngivuma kubayincenye yelucwaningo?

Uceleka kutsi ubeyincenye yemibuto letokwenteka ekhaya lakho. Lemibuto itobuka tidzingo nebumatima bebanakekeli bemndeni nekutsi bangasekelwa kanjani . Lemibuto itowentiwa egumbini lelinekuthula kuze kubete kuphatamiseka. Lemibuto itotsatsa imizuzu lengemashumi lasitfupha. Nangabe uvuma kubayincenye yalolucwaningo, kutobakhona kutsebula ngesikhatsi semibuto, kani lokushiwako kutohlwe kubhalwa phansi.

Kutoba yimfihlo yini kubayincenye yalolucwaningo?

Njenemucwaningi, ngitociniseka kuvikelwa kwekwatiwa kwakho kanye naloko lotobe ukushito. Kuze kutsi ungatiwa, libito lakho angeke lifakwe kuloko lokushito. Kuciniseka kuvikeleka kwakho, libito lakho, Kanye nelemndeni wakho, ngeke lifakwe kuloko lokutobe kutsebuliwe nome kubhalwe phansi. Tinombolo titofakwa kuloko lokushito futsi ngumcwaningi kuphela lotokwati kutsi lenombolo yabani. Kuciniseka kufihleka kwakho, imininingwane lebhalisiwe itovalelwa ekhabetheni lelikhiywako kanye naku ngcondvo mshini lovikelwe. Uma ngikhetsa kubhala umbiko ngalolucwaningo, kwatiwa kwakho kanye nekwemndeni wakho kutovikelwa.

Yini bungoti balolucwaningo?

Lonkhe lucwaningo lelentiwa kubantfu lunesigaba sebungoti. Kepha ke, sitozama konkhe lokusemandleni kutsi bungoti bungabibikho futsi sikuphe lusito uma utivela ungakaphatseki kahle engcondwveni noma nganguyiphi indlela lucwaningo lusentiwa. Nakudzingekile, utochunyaniswa nemeluleki longu Mercy Shabangu (+268 76986918).

Yini inzunzo yalelucwaningo?

Lolucwaningo alukentelwa kuzuza wena kepha imiphumela itokwenta kutsi sati kabanti ngetidzingo nebumatima bebanakeleli bemndeni lababhekene nabo ekunakekeleni tihlobo tabo letinamdlavuza emakhaya. Siyetsemba esikhatsini lesitako, litiko letempilo lingazuza kulelicwaningo ngekwati kabanti ngaletidzingo tebanakekeli bemndeni ngekunakelela tihlobo emakhaya.

Kufanele yini ngibe yincenye yalolucwaningo, nekutsi ngingayeka yini noma nini?

Kubayincenye kwakho yalolucwaningo kungekufisa kwakho. Ungakhetsa kungabi yincenye yalolucwaningo. Uma ukhetsa kuba yincenye yalolucwaningo, ungayeka noma nini. Uma ukhetsa kungabi yincenye noma uyeka noma nini, ngeke ujeziswe noma ulahlekelwe nguloko lokuyinzuzo ngetemphilo lekufanele ukutfole.

Nangabe nginemibuto ke?

Lolucwaningo lwentiwa ngu Mamba Nompumelelo, umfundzi weNyuvesi yase Western Cape. Uma unemibuto ngelucwaningo, tsintsa Mamba Nompumelelo kunati tinombolo: (mahlalekhukwini +268 76119808), (likhasi langcondvo mshini melelo2244@gmail.com).

Uma unemibuto ngemalungelo akho mayelana nelucwaningo noma kunetinkinga lohlangene nato mayelana nelucwaningo, cela utsintse:

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Lelicwaningo lutfole imvumo eNyuvesi yase Western Cape kulabo labasekomidini lako kubuka emacwaningo.

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ANNEXURE 3: Informed Consent Sheet (English)

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Informed consent form

Title of research project: The perceived needs and challenges of family caregivers in providing palliative care for relatives living with cancer in the Hhohho Region, Kingdom of Eswatini.

The study has been described to me in a language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

___ I agree to be audiotaped during my participation in this study.

___ I do not agree to be audiotaped during my participation in this study.

Participant's name………………………..

Participant's signature……………………………….

Date………………………

Biomedical Research Ethics Committee

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ANNEXURE 4: Informed consent form (Siswati)

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Lifomu lemvumo

Sihloko selucwaningo: Tidzingo nebumatima bebanakekeli bemndeni ekunakeni tihlobo tabo letinamdlavudla emakhaya, esifundzeni saka Hhohho, eveni lase Swatini.

Lolucwaningo luchazwe kimi ngelulwimi lengilwatiko. Imibuto ngalelicwaningo lebenginayo iphendvuliwe. Ngiyacondza kutsi kusho kutsini kimi kubayincenye yalolucwaningo futsi ngiyavuma kutsi kuba yincenye yelucwaningo kusifiso sami. Ngiyati kutsi kutoba yimfihlo kubayincenye yalolucwaningo. Ngiyacondza kutsi ngingayeka noma nini kubayincenye yalolucwaningo ngaphandle kwekunika tizatfu nekwesaba kutsi kungahle kube nalokubi lokungangehlela nome kulahlekelwa tinzunzo.

____ Ngiyavuma kutsebulwa ngiseyincenye yelucwaningo.

____ Angivumi kutsebulwa ngiseyincenye yelucwaningo.

Libito laloyincenye yelucwaningo………………………..

Sidladla sakhe……………………………….

Lusuku………………………

Biomedical Research Ethics Committee

University of the Western Cape

Private Bag X17

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ANNEXURE 5: Interview guide (family member still alive) English

Interview schedule for family caregivers who are still looking after their relative.

Read out information sheet introducing yourself and the research project. Request permission to audio record the interview. Take written consent.

General information

Age:

Sex:

Area:

Employment status:

Educational level:

Number of persons living in household:

Relationship of each of these to the patient:

The patient's journey: from diagnosis to treatment:

I would like to start off by finding out a little about the patient and their history.

1. Can you tell me when they were diagnosed with cancer?

2. What type of cancer does the patient suffer from?

3. What type of treatment did (the patient) receive?
4. Over what period of time did they receive this treatment?

   (Probe if treatment still on-going)
5. Which institution did they receive it from?
6. How long have you been taking care of (the patient)?

The palliative care phase:

1. When was the decision made that (the patient) required palliative care?
2. Who were involved in making the decision?
3. What were your initial thoughts about this decision?
4. Were there any concerns you had about providing home-based palliative care?
5. What practical advice and information were you given from hospital about the care you had to provide?
6. What medical supplies were you given from hospital?

   (Probe if supplies were helpful and if they were sufficient)

Providing home-based care:

1. Can you tell me about your experience of taking care of your family member? How has it been for you?

2. Were there aspects of the home-based care that you felt were relatively easy to manage when looking after the patient?

   (Probe if there were any, what they were and why they were easy to manage)

3. Have you experienced any particular challenges whilst looking after (the patient)?

   (Probe if any, what they are and how they overcame each of them)

4. What support do you get from other members of the household in looking after the (patient)?

5. What support did you get from other people (eg. community members) and community based organizations (eg. HBC NPO) in looking after (the patient)?

6. What support do you receive from the health services?

7. Have you had any needs that you feel you could have got more support on, for example, needs related to information or medical supplies or counselling, or things your family might have needed because the (patient) is ill?

   (Probe if any needs and specifically what they are and how they were met. Consider the *range* of needs from material/resource needs to psycho-social and spiritual needs)

8. How best do you believe healthcare workers can support someone like yourself, in caring for a family member who has terminal cancer and requires palliative care in the home?

   (Probe if any, what types of support?)

9. What practical assistance would you hope the Ministry of Health would make available for family caregivers providing home-based cancer palliative care within communities?

Ask the interviewee if they have any questions they would like to pose.

ANNEXURE 6: Imibuto (lilunga lemndeni lelisaphila) Siswati

Imibuto yemunakekeli losanakelela lilunga lemndeni.

Fundza lokwatisa ngelucwaningo ngitatise kutsi ngingubani nekutsi lingani lucwaningo. Cela imvumo yekutsebula. Tsatsa imvumo lebhaliwe.

Lokwatisa ngaloyincenye yelucwaningo

Umnyaka:

Bulili:

Indzawo:

Umsebenti:

Inombolo yebantfu labahlala kulendlu:

Budlelwane babo nalogulako:

Luhambo lwalogulako: kusukela ekwatini ngekugula kanye nekwelaphwa

Ngingatsandza kucala ngekwati ngalogulako nekutsi kusuka kuphi.

1. Ngicela ungitjele kutsi watinini kutsi unamdlavuza?
2. Unaluphi luhlobo lwamdlavuza?
3. Nguluphi luhlobo lwekelashwa (logulako) lalutfolile?
4. Ulashwe sikhatsi lesinganani ngaloluhlobo?

(Buta kabanti uma kwelashwa kusachubeka)

5. Ngusiphi sibhedlela latfola kwelashwa kuso?
6. Unesikhatsi lesinganani unakekela (lologulako)?

Libanga lekunakekela:

1. Satsatfwa nini sincumo sekutsi (lologulako) udzinga kunakekelwa?
2. Bobani lababa yincenye yalesincumo?
3. Kwabayini imicabango yakho ngalesincumo ekucaleni?
4. Kukhona yini lowakhatsateka ngako ngekunakekela ekhaya?
5. Ngukuphi kwelulekwa nelwati lenanikwa lona esibhedlela ngalokunakekela lokufanele ukwente?
6. Yini tinfo tekusita lenanikwa tona esibhedlela?

   (Buta kabanti kutsi kwabalusito yini nekutsi kwenela yini)

Libanga lekunakekela ekhaya:

1. Cela ungatise ngalohlangabetene nako usanakekela lilunga lemndeni wakho? Kubenjani kuwe?
2. Kukhona yini incenye yekunakekela ekhaya lobuwuva ngatsi ilula kuwe usanakekela lologulako?

(Buta kabanti uma kukhona, nekutsi kuyini, nekutsi leni kubelula)

3. Kukhona yini bulukhuni lohlangabetene nabo usanakekela (lologulako)?

   (Buta kabanti nakukhona, kutsi kwakuyini, nekutsi ukuncobe njani ngakunye ngakunye)

4. Kukhona yini lusito lolutfolako kulamanye emalunga emndeni ekunakekeleni (lologulako)?

5. Kukhona yini lusito lowulitfole kulabanye bantfu (njengebantfu bemmango) kanye netinhlangano letisita emmangweni (letifana naleto letinika lusito emakhaya, noma leto letingayenti inzuzo) ekunakekeleni (lologulako)?

6. Ngukuphi kwesekelwa lokutfolako emtfolampilo?

7. Ubenato yini tidzingo lowuva ngatsi ngabe utfole kwesekelwa lokungetulu, njengetidzingo letifana netelwati noma lokukwekunakekela noma kukhulunyiswa ngekwengcondvo noma tintfo umndeni lake atidzinga ngoba (lologulako) aphatsekile?

   (Buta kabanti uma tibekhona nekutsi tabayini nekutsi tihlangabeteke kanjani)

8. Ucabanga kutsi tisebenti tetempilo tingamusekela kanjani umuntfu losesimeni lesifana nesako, ekunakekeleni lilunga lemndeni lelinamdlavuza lelidzinga kunakekelwa ekhaya?

   (Buta kabanti uma lukhona, nekutsi kungabakanjani lokwesekelwa?)

9. Nguluphi lusito longafisa kutsi litiko letempilo lungenta kutsi lubekhona emmangweni ekusiteni banakekeli balabagula ngamdlavuza emakhaya?

Buta loyincenye yelucwaningo kutsi ikhona yini imibuto lafise kuyibuta.

ANNEXURE 7: Interview guide (Lost family member) English

Interview schedule for family caregivers who lost their family members in the last 18 months.

Read out information sheet introducing yourself and the research project. Request permission to audio record the interview. Take written consent.

General information

Age:

Sex:

Area:

Employment status:

Number of persons living in household:

Relationship of each of these to patient:

The patient's journey: from diagnosis to treatment:

I would like to start off by finding out a little about the patient and their history.

1. Can you tell me when they were diagnosed with cancer?
2. What type of cancer did the patient suffer from?
3. What type of treatment did (the patient) receive?
4. Over what period of time did they receive this treatment?

(Probe if treatment was completed)

5. Which institution did they receive it from?
6. How long did you take care for (the patient)?

The palliative care phase:

1. When was the decision made that (the patient) required palliative care?
2. Who were involved in making the decision?
3. What were your initial thoughts about this decision?
4. Were there any concerns you had about providing home-based palliative care?
5. What practical advice and information were you given from hospital about the care you had to provide?
6. What medical supplies were you given from hospital?

   (Probe if supplies were helpful and if they were sufficient)

Providing home-based care:

1. Can you tell me about your experience of taking care of your family member? How was it for you?
2. Were there aspects of the home-based care that you felt were relatively easy to manage when looking after the patient?

   (Probe if there were any, what they were and why they were easy to manage)

3. Did you experience any particular challenges whilst looking after (the patient)?

   (Probe if any, what they were and how they overcame each of them)

4. What support did you get from other members of the household in looking after the (patient)?

5. What support did you get from other people (e.g. community members) and community-based organizations (e.g. HBC NPO) in looking after (the patient)?

6. What support did you receive from the health services?

7. Did you have any needs that you felt you could have got more support on, for example, needs related to information or medical supplies or counselling, or things your family might have needed because the (patient) is ill?

   (Probe if any needs and specifically what they are and how they were met. Consider the *range* of needs from material/resource needs to psycho-social and spiritual needs).

8. How best do you believe healthcare workers could support someone like yourself, in caring for a family member who had terminal cancer and required palliative care in the home?

   (Probe if any, what types of support?)

9. What practical assistance would you hope the Ministry of Health would make available for family caregivers providing home-based cancer palliative care within communities?

Ask the interviewee if they have any questions they would like to pose.

ANNEXURE 8: Interview guide (Lost family member) Siswati

Imibuto yemunakekeli lowashonelwa lilunga lemndeni etinyangeni letilishumi nasiphohlongo letengcile.

Fundza lokwatisa ngelucwaningo ngitatise kutsi ngingubani nekutsi lingani lucwaningo. Cela imvumo yekutsebula. Tsatsa imvumo lebhaliwe.

Lokwatisa ngaloyincenye yelucwaningo

Umnyaka:

Bulili:

Indzawo:

Umsebenti:

Inombolo yebantfu labahlala kulendlu:

Budlelwane babo nalogulako:

Luhambo lwalogulako: kusukela ekwatini ngekugula kanye nekwelashwa

Ngingatsandza kucala ngekwati ngalogulako nekutsi kusuka kuphi.

1. Ngicela ungitjele kutsi watinini kutsi unamdlavuza?
2. Bekanaluphi luhlobo lwamdlavuza?
3. Nguluphi luhlobo lwekelashwa (lobekagula) lalutfola?
4. Ulashwe sikhatsi lesinganani ngaloluhlobo?

(Buta kabanti kutsi kwelashwa kwaphela yini)

5. Ngusiphi sibhedlela latfola kwelashwa kuso?
6. Wabanesikhatsi lesinganani unakekela (lobekagula)?

Libanga lekunakekela:

1. Satsatfwa nini sincumo sekutsi (labekagula) udzinga kunakekelwa?
2. Bobani lababa yincenye yalesincumo?
3. Kwabayini imicabango yakho ngalesincumo ekucaleni?
4. Kukhona yini lowakhatsateka ngako ngekunakekela ekhaya?
5. Ngukuphi kwelulekwa nelwati lenanikwa lona esibhedlela ngalokunakekela lokufanele ukwente?
6. Yini tinfo tekusita lenanikwa tona esibhedlela?

   (Buta kabanti kutsi kwabalusito yini nekutsi kwenela yini)

Libanga lekunakekela ekhaya:

1. Cela ungatise ngalohlangabetene nako ekunakekeleni lilunga lemndeni wakho? Kubenjani kuwe?
2. Kukhona yini incenye yekunakekela ekhaya loweva ngatsi ilula kuwe ekunakekeleni labekagula?

   (Buta kabanti uma kwakukhona, nekutsi kwakuyini, nekutsi leni kwabalula)

3. Kukhona yini bulukhuni lowahlangabetana nabo usanakekela (lebekagula)?

   (Buta kabanti nakwakukhona, kutsi kwakuyini, nekutsi wakuncoba njani ngakunye ngakunye)

4. Kukhona yini lusito lowalutfola kulamanye emalunga emndeni ekunakekeleni (labekagula)?

5. Kukhona yini lusito lowalutfola kulabanye bantfu (njengebantfu bemmango) kanye netinhlangano letisita emmangweni (letifana naleto letinika lusito emakhaya, noma leto letingayenti inzuzo) ekunakekeleni (labekagula)?

6. Ngukuphi kwesekelwa lowakutfola emtfolampilo?

7. Wabanato yini tidzingo loweva ngatsi ngabe utfole kwesekelwa lokungetulu, njengetidzingo letifana netelwati noma lokukwekunakekela noma kukhulunyiswa ngekwengcondvo noma tintfo umndeni lake atidzinga ngoba (labekagula) aphatsekile?

   (Buta kabanti uma tabakhona nekutsi tabayini nekutsi tahlangabeteka kanjani)

8. Ucabanga kutsi tisebenti tempilo tingamusekela kanjani umuntfu labesesimeni lesifana nesako, ekunakekeleni lilunga lemndeni lelinamdlavuza lelidzinga kunakekelwa ekhaya?

   (Buta kabanti uma lukhona, nekutsi kungabakanjani lokwesekelwa?)

9. Nguluphi lusito longafisa kutsi litiko letempilo lungenta kutsi lubekhona emmangweni ekusiteni banakekeli balababagula ngamdlavuza emakhaya?

Buta loyincenye yelucwaningo kutsi ikhona yini imibuto lafise kuyibuta.

ANNEXURE 9: Permission letter to conduct study (Eswatini ethics)

RESEARCH PROTOCOL CLEARANCE CERTIFICATE

BOARD REGISTRATION NUMBER	**FWA 00026661/IRB 00011253**					
PROTOCOL REFERENCE NUMBER	**SHR217/2020**					
Type of Review	Expedited	X		Full Board		
Name of Organization	Student (Master's)					
Title of study	The perceived needs and challenges of family caregivers in providing palliative care for relatives living with cancer in the Hhohho Region, Kingdom of Eswatini.					
Protocol version	1.0					
Nature of protocol	New	X		Amendment		Renewal
List of study sites	Hhohho Region Communities					
Name of Principal Investigator	**Ms. Mamba, Nompumelelo Sindisiwe**					
Names of Co- Investigators	N/A					
Names of steering committee members in the case of clinical trials	N/A					
Names of Data and Safety Committee members in the case of clinical trials	N/A					
Level of risk (Tick appropriate box)	Minimal ✓			High		
Clearance status (Tick appropriate box)	Approved	X		Disapproved		
Clearance validity period	Start date	**22/05/2020**		End date	**22/05/2021**	
Signature of Chairperson						
Date of signing	**23/05/2020**					
Secretariat Contact Details	Name of contact officers			Ms Babazile Shongwe		
	Email address	ethicsswaziland@gmail.com				
	Telephone no.	**(00268) 24044810**				

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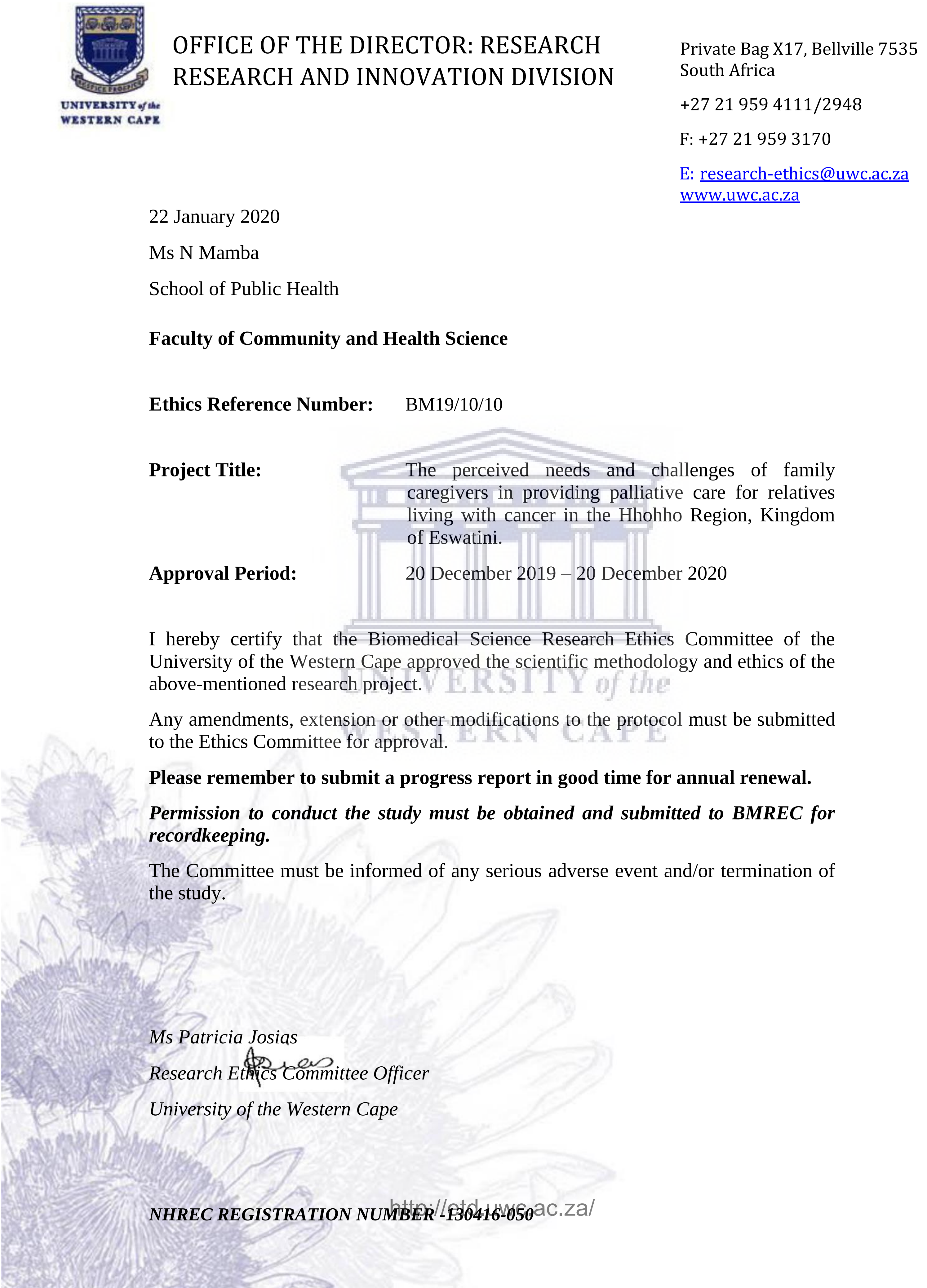
EHHRRB

ANNEXURE 10: Permission letter to conduct study (UWC)



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22 January 2020

Ms N Mamba

School of Public Health

Faculty of Community and Health Science

Ethics Reference Number: BM19/10/10

Project Title: The perceived needs and challenges of family caregivers in providing palliative care for relatives living with cancer in the Hhohho Region, Kingdom of Eswatini.

Approval Period: 20 December 2019 – 20 December 2020

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above-mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

Please remember to submit a progress report in good time for annual renewal.

Permission to conduct the study must be obtained and submitted to BMREC for recordkeeping.

The Committee must be informed of any serious adverse event and/or termination of the study.

Ms Patricia Josias

Research Ethics Committee Officer

University of the Western Cape

NHREC REGISTRATION NUMBER -130416-050