THESIS / DISSERTATION

A STUDY TO EXPLORE FACTORS THAT INFLUENCE FAMILY CAREGIVERS OF PATIENTS RECEIVING PALLIATIVE CARE FROM ISLAND HOSPICE TO SEEK HELP AT EMERGENCY UNIT IN HARARE, ZIMBABWE

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Abstract

Background: *This study investigated the factors that influence family caregivers of patients receiving palliative care from Island Hospice to seek help at emergency unit. The study was conducted at Island Hospice Service in Harare, Zimbabwe where Palliative care has been practiced in Zimbabwe since 1979 mainly using the home-based care model where patients are cared for by family caregivers with the support of the palliative care teams.* ***Aim:*** *To explore and understand issues that influence family caregivers at Island Hospice to seek help at emergency units for patients who are terminally ill.* ***Method:*** *This was a phenomenological study using semi-structured qualitative interviews with fifteen adult family caregivers who were the main carers of Island Hospice patients who presented at the emergency unit during the January to September 2015 period. Data were collected in Shona language using semi structured digitally recorded interviews. Data analysis through identifying themes that emerged from the transcripts.* ***Results:*** *Family caregivers reported the need for availability of palliative care medicine and other resources in the home setting. The family caregivers reported the need to be given information regarding the patient's diagnosis and prognosis as that would prepare them emotionally. They described challenges as pressure from relatives, witchcraft issues as well as lack of practical skills in providing care.*

Conclusion *Considering the lack of resources and support the respondents do not support the idea of home deaths, they would rather send patients to the emergency rooms. A more organized end of life care and support for family caregivers and patients could be instituted by the hospice organization.*

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Acronyms

AIDS	Acquired Immune Deficiency Syndrome
APCA	African Palliative Care Association
CBO	Community Based Organization
CHBC	Community Home Based Care
HIV	Human Immunodeficiency Virus
HOSPAZ	Hospice Association of Zimbabwe
IHS	Island Hospice Service
MOHCC	Ministry of Health and Child Care
MRCZ	Medical Research Council of Zimbabwe
PLWHA	People Living With HIV/AIDS
WHA	World Health Assembly
WHO	World Health Organization
UCT	University of Cape Town

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CHAPTER 1: INTRODUCTION

1.1 Introduction

The chapter introduces the research study with a background to the problem. Family caregivers play a pivotal role in providing palliative care to patients in the comfort of their homes. It has been estimated that in up to 90 percent of illness, care may be provided in the home by family caregivers and that up to 80 percent of AIDS-related deaths occur in the home. Schumacher (2008) and other researchers from the developed world especially UK suggest that people would prefer to die at home even though some end up dying in hospital.

Palliative care supports the notion of home deaths, the concept of patient autonomy is an ethical issue in palliative care. This means that patients have the right to make choices that affect their health and treatment. It therefore behoves the palliative care team to support the choices made through giving information and offering services to support the choice made. The patient's choices go beyond choosing treatment options and extend to choosing a place of death.

In his book Dying at Home, Doyle (1998) stated that most patients receiving palliative care prefer to be cared for and even die at home, under the care of family caregivers. Harding (2012) also reaffirms these sentiments. Palliative care practice is crucial as the family caregivers are supported to enable them to care for patients during the continuum of care until time of death either at home or in a health centre.

The World Health Assembly (WHA) resolution of 2014 advocated for palliative care to be practised globally for the benefit of the patient and families. The resolution declared that all

governments should make access to hospice and palliative care for their nationals. To that extent, palliative care is a human right which should be included in governments' national health strategies. The resolution stipulated that governments should strive to make hospice and palliative care available to all citizens, using different models which are applicable to their settings. Palliative care should be taught to all health professionals including community health workers so as to ensure the provision of palliative care at all levels of health care.

The WHO (2002) emphasizes the need for bereavement support to surviving family members as an integral component of palliative care. It further highlights that an interdisciplinary team is necessary to enhance the provision of total care for the patient and family. The limitations of palliative care in Africa as highlighted by Powel *et al* (2013) are that some patients start receiving care at a very late stage of the disease when they no longer benefit from curative interventions. This may be as a result of cultural and spiritual issues where patients consult traditional healers, faith healers as well as using other forms of alternative medicine and treatment instead of palliative care. Moreover there is no formal referral from traditional to conventional medicine; also the methods of treatment differ as well as no documentation from traditional healers to show for the care provided.

What is crucial is for palliative care to begin at diagnosis where patients are referred soon after diagnosis. The public health approach to palliative care provision according to Stjernsward *et al* (2007) highlights the need for training health professional as well as community health workers in the provision of palliative care. There is a need for development of palliative care policies which will support palliative care and training. That together with the availability of palliative care medications including Opioids will ensure access of quality palliative care. Training should also be extended to clergy, traditional and

faith healers as well as modern day prophets. Even though The World Health Assembly resolution (2014) advocated for palliative care among member states, palliative care is developing at a slow pace in some third world countries where patients are referred to hospices and the challenge is that hospices do not offer services to the whole country.

The ideal situation would be to have government and private hospitals also practise palliative care to ensure equity. There should also be a national monitoring and evaluation system of palliative care to ensure that there is accountability for the development of palliative care. The training and capacity building component should have a strong mentoring programme to enhance palliative care skills among health professionals globally. Apathy and lack of knowledge from governments results in lack of appreciation for the value of palliative care. This is compounded by lack of palliative care policies to support the service as well as lack of trained professionals to teach and practise palliative care. Palliative care indeed is important in our modern world. As a consistently evolving phenomenon it is important to conduct advocacy and research to ensure more current and up to date information on palliative care.

1.2 Background to the Study

Merriman (2002) stated that home-based palliative care is the commonest model of palliative care delivered in most African countries where care is provided at home mainly by a family member or other relatives. The home-based palliative care model has been documented by various scholars as having advantages to the family, the community as well as the patients.

Family caregivers play a crucial role in ensuring the provision of a continuum of care and support to patients at home who are on palliative care programme. In addition the family caregivers also assume many of the patient's domestic responsibilities, and they may have to forgo their own social activities and work duties to assume the role of a primary caregiver

and thus perform the duties required of them. Robson (2000) noted that most of the care giving burden is carried by women and girls. In some instances girl children may abandon school to carry out care giving duties for a family member. Even though the family caregivers are willing to provide the care to their loved ones at home, they may have other issues affecting their provision which include lack of knowledge as well as lack of caring skills regarding provision of physical care. Issues of attitudes, culture and spirituality for the family caregivers may hinder the quality of care being provided to the patients.

Palliative care has been practised in Zimbabwe since 1979, using the home-based care model where patients are cared for by family caregivers with the support of the palliative care teams. It was noted that in Zimbabwe 1 in 60 people including children and adults of the total population require palliative care most of which is provided through the home-based approach model (WHO, 2004). The palliative care team provides physical, emotional, social and spiritual support to the patient and family throughout the trajectories of illness. The home-based palliative care model has reduced the bed occupancy in Zimbabwe's hospitals. There is a National Home Based Care Policy, a National Palliative Care Policy at final draft level, National Palliative Care Standards as well as Home Based Care Standards Document in Zimbabwe.

The availability of these policies and policy documents has supported the home-based palliative care provision in the country. Moreover this model of care has improved the quality of care provided by family caregivers as they are supported by the palliative care team.

In as much as palliative home care has numerous advantages to the patient and family, it places great challenges on the family caregivers. Walton (2011) highlighted that in some instances the family caregivers may be required to make tough decisions regarding care of the

patient, which benefit or harm the patient. Farrell *et al* (1993) reiterated the same point regarding the importance of supporting family caregivers. The support and information provided to the family caregivers includes discussions about the patient's disease, which includes clearing misconceptions about the diagnosis and answering questions asked as well as giving information regarding symptom aetiology and possible prognosis. Family caregivers require information regarding measures to make the patient comfortable, conversations regarding disease progression as well as provision of medical equipment.

Families cope better where they are provided with emotional support and taught how to provide physical care of the patient in the home. Preparation for death should be done gradually as the patient begins to deteriorate. However, Keli *et al* (1998) argue that despite the support being provided to the family, there are some instances where a home death may cause distress to the family due to challenges. In working with the family and patients at home, the palliative care team develops a care plan in line with the symptoms being experienced by the patient. The main objective of formulating care plans is to ensure comfort for the patient, enhancing quality of care, promoting dignity in dying and meaningful communication with the family. The care plan is regularly updated by the team with the involvement of the patient and family in planning appropriate care for the patient. However, despite ongoing communication with the family and patient regarding patient's condition and needs, as well as providing care to the patient which includes pain and symptom management, throughout the disease trajectory, it has been noted that when patients present with new symptoms or reach end of life, some families take the patients to the emergency unit. The staff in the emergency may fail to identify the palliative care patients as they present, the patients may be in the last trajectories of their illnesses. Unfortunately the patients end up being managed as acute cases instead of being managed as chronic cases. The

prevailing trend has been that some patients have been taken to the emergency unit while they are dying.

Gwyther *et al* (2012) in their guidelines on provision of end of life care describe that as death approaches, the patient may become profoundly weak, spending most of his/her time in bed. The patient becomes perpetually drowsy and will spend extended periods sleeping and may at times seem unresponsive, difficult to rouse, withdrawn, or semi comatose but the patient will still be hearing as hearing is described as the last sense to go. The patient will lose interest in food and drink, or feel very thirsty and may become disoriented as well as having a limited attention span. The patient's urine output decreases and it becomes concentrated, however the patient may lose control of bladder and or bowels as the muscles in this area begin to relax. The breathing pattern may change, where the patient will have rapid shallow breathing with periods of no breathing, this is referred to as Cheyne-Stokes respiration. There may be gurgling sounds in the patient's chest which may become very loud referred to as 'Death Rattle' however this does not distress the patient though is unpleasant for the carers.

The care of the terminal patients provided at the emergency rooms depends on the palliative care knowledge of the one attending to the patient. The staff in the emergency unit, if not trained in palliative care, may fail to identify the chronic patients as they present, who may be in their last trajectories of their illnesses and they end up providing acute care to these terminally ill patients. Therefore it is important to train all health professionals in palliative care so that they can use the knowledge and skills when they encounter patients requiring palliative care in their different areas of practice. Beckstrand *et al* (2008) postulated that that the emergency unit is not considered an ideal place for patients under palliation as the

outcome may not be favourable for these types of patients as they will be in need of relieving distressing symptoms and ensuring that they are comfortable until time of death.

1.3 Purpose of the Study

The study focused on family caregivers whose patients were under the care of Island Hospice, to investigate issues regarding provision of home-based palliative care. It was mostly concerned about family caregivers sending patients from their homes to the emergency unit during the course of illness. This resulted in some patients being admitted, dying in hospitals or dying on the way to the emergency unit. This research aimed to explore factors that influence family caregivers of patients under the palliative care programme to take patients to the emergency rooms.

1.4 Island Hospice and Health Care

Island Hospice and Health Care (Island) is a local NGO, based in Harare, Zimbabwe working closely with the Ministry of Health and Child Care and Hospice Association of Zimbabwe

(HOSPAZ) to meet the increased demand for palliative care in face of the HIV and AIDS pandemic and cancer. It was established in 1979 as the first Hospice in Africa and is registered as a welfare organisation.

The organization's vision is: A Zimbabwe where people access quality palliative and bereavement care to reduce suffering and pain and improve the quality of their lives.

The Mission Statement indicates that Island Hospice and Healthcare, being a centre of excellence provides quality palliative care services and support to those with life threatening illnesses and the bereaved through comprehensive direct care, capacity development, partnerships research and advocacy.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

The review begins with an overview of palliative care, followed by definition of key concepts related to palliative care. After this a review of the impacts of palliative and family caregivers caring for patients with terminal conditions in their homes. The chapter describes the experiences, challenges, cultural issues and the dying process. Attention is given to the support systems and gaps of caregivers at home and what causes them to be overwhelmed by the care giving process resulting in them sending them back to hospital. Finally the review focuses on other economic and social issues related to death and dying.

The sources of review included official publications, non official publications, dissertations, books, theses, pamphlets, journals and online publications. This search of the literature was identified using search terms listed and within dates 1977-2011 provided. The researcher was only able to obtain literature about the experiences of the dying from the developed world. No articles of relevance to the Zimbabwean and African setting were found, the search was therefore widened to other continents where some literature was found

2.2 Palliative care

The World Health Organisation, WHO (2015) defines palliative care as an approach to care that deals with issues in a patient, and their family arising from a chronic or terminal illness, with the aim of improving their quality of life. The care includes physical, emotional, spiritual, cultural and social which is referred to as provision of total care or holistic care. The National Council for Hospice and Specialist Palliative care Services NCHSPCS (2004) emphasizes that the goal of palliative care is to ensure the best possible quality of life for

patients and their families regardless of stage of disease as well as conserving the patient's dignity. According to Lumanais *et al* (2012) palliative care should begin early at diagnosis where the patient will be receiving disease modifying therapies along with palliative care such as ART, chemotherapy, surgery or radiotherapy. It encompasses the illness trajectories of different diseases. Palliative care is most effective when considered early in the course of the illness and continues through the continuum of care. Early palliative care not only improves quality of life for patients but also reduces unnecessary hospitalizations and use of health-care services.

Among all the components of health in the National Health System, palliative care is one of the critical components that play an important role in the care of patients living with chronic and life threatening illnesses. Hanks (2010) documented that palliative care is cross-cutting benefitting all ages as well as people in different life circumstances. McCann (1990) highlighted the need for palliative care for older persons. There are similarities as well as differences in the provision of palliative care for different groups. Both aspects provide support to families and the patient. Palliative care extends to the provision of bereavement support to surviving family members. The use of the interdisciplinary team approach is recommended to ensure provision of total care through the involvement of other team members. Specific attention is given to relieving and preventing suffering at end of life .For example in palliative care for older persons symptoms can present differently, due to the physiological changes associated with the aging process. In older persons medications and dosages are more complexx and age can affect quality of life. Diseases of childhood are complex and diverse, including those with congenital abnormalities, genetic syndromes. In children symptoms can present differently. Assessment for children can be challenging, even medications and dosages are more complex. Palliative care is also applicable in poor resource

settings though shortages of material and human resources hinder care provision. Holistic care involves much more than drugs and physical care. It emphasizes on the care of a whole person; incorporating physical, psychological, social and spiritual aspects. Merriman (2002) reiterates that holistic care involves caring for a patient as a whole being, in totality not only the physical aspect. Meanwhile Byock (2008) highlighted the importance of providing palliative care to people with life-threatening illnesses as well as patients with end stage organ failures such as the following: Cancer, Heart disease, Lung diseases, Kidney failure, Dementia, HIV/AIDS and ALS (amyotrophic lateral sclerosis)

2.3 Home-based Palliative Care Model

The African Palliative Care Association (APCA) (2004) highlights that there are different models of palliative care provision of which the home-based care model is the best and most feasible one for most African countries. In home care, the care providers are mostly untrained family members who may have never cared for a chronically or terminally ill patient before therefore this will be their first experience. The duration of caring for the patient depends on the patient's condition. The experience of providing care to the patients may affect the family caregiver positively or adversely. The task may be daunting but with the support from the palliative care team, the caregivers are able to provide care for the patients at home. Wilkinson (2010) supported the concept of proving support to family caregivers in that family members cope better with the care and support they get from the palliative care team. Graham (1989) documented some of the advantages of home-based palliative care being that the patient will have fewer trips to the emergency rooms or health centre for management of pain and other distressing symptoms. Home care results in better outcomes if patients use their medications correctly, and family is supported by the palliative care team throughout.

Home care has been practised in Zimbabwe since long before the advent of palliative care. The difference was that the home-based care practised was lacking the holistic and multidisciplinary team approach components that are in palliative care. Robson (2000) argues against home-based care provision as it is mostly provided by women and girls, who are already vulnerable. The family caregivers are individuals who need individualized assessment regarding their care giving experience as well as information and support during their caring journey (Harding *et al* 2008).

2.4 The Emergency Unit

The Emergency unit is a place in a hospital where patients are taken to by family members for the purpose of seeking urgent care for the patient (Mierendorf 2014). The main purpose of Emergency unit is "to treat undifferentiated patients across age and disease or injury spectra, to resuscitate and stabilise in order to establish initial or definitive treatment, and finally to discharge the patient to an appropriate facility". The emergency unit does not discriminate patients even patients who are under the home-based care have a right to be taken to the emergency unit. When patients present at the emergency unit triaging is done for every patient. Category is for critically sick patients, sick patients, stable patients and deaths. For stable patients, they are attended to as outpatients. Sick patients are supposed to be seen by a doctor immediately or as soon as possible. Critically sick patients are attended to in the emergency room where all resuscitation equipment is available. The doctor attends to the patient and other departments such as theatre and ICU are on high alert. For deaths, all patient confirmed dead, the one in charge in the department or a senior member of staff attends to the family for breaking of bad news. The team gets to know whether the patient had a life-threatening or chronic illness after or during the process of breaking the bad news of the

death. This comes out during the process of finding out about how the patient has been and whether patient had a chronic condition.

The challenge is that when palliative care patients who have reached end present at the emergency unit, they receive increasingly invasive care which is not necessary or the patients end up being admitted in hospital. This may be against their will as some would have talked about dying at home to the family caregivers. Wass *et al* (1988) documented that some patients who have reached end of life experience a dying process that does not comply with the concept of a good death if they are in the emergency unit. The World Health Assembly resolution (2014) advocates for training for all health professionals working in all departments so that they can use their skills when the opportunity arises. However, Twycross and Litcher (2003) emphasise the need to involve family members during history taking, and care planning to avoid subjecting the patient to unnecessary investigations. This can also be done in the emergency unit. Twycross and Litcher (2003) further documented that communicating with family and preparation for death when the patient has reached end of life would help family in ensuring that the patient is not subjected to unnecessary resuscitative procedures when actively dying. Family's coping with impending death also depends on the quality and amount of preparation done by the palliative care team. If the family was not prepared fully, they will agree to patient being resuscitated which is an infringement of the dying person's rights. The patients under the palliative care programme with advanced disease would have communicated their wishes regarding choice of place of death. Another way would be to have a palliative care specialist on call who will attend to such cases as they are referred. This will ensure that palliative care is being practised in the emergency unit.

2.5 Family Caregivers

Walton (2011) highlighted that family caregivers play a crucial role in ensuring the provision of the continuum of care and support to terminally ill patients at home. In addition they also assume many of the patient's domestic responsibilities, and they may have to forgo their own social activities and work duties to assume the role of a caregiver and thus perform the duties required of them. Grande (2009) postulated that care givers also experience adverse effects of care giving such as depression and anxiety. In some instances the family caregivers may be required to make tough decisions regarding care of the patient, these decisions may benefit or harm the patient, in some instances the girl children may abandon school to carry out care giving duties for a family member which will affect their lives forever with no formal education. Women abandon their income generating jobs to provide care which contributes to their poverty stricken status. UN AIDS (2010) provided evidence that the main caregivers in palliative home-based care programmes are women, some of whom are living with HIV and are on antiretroviral therapy. Moreover most of the women providing the care giving have major social, economical and psychological challenges which also need to be addressed in the process of providing care to the patient and family (Muula, *et al* 2005). However, Hudson et al (2010) highlighted that family caregivers caring for patients who had reached end of life find it challenging to provide the required care. Some of them are overwhelmed by the symptoms as patients reach end of life.

However, despite the recognition of the vital care work that the family caregivers do, the family caregivers are not sufficiently supported by the health professionals as well as by the other family members. Jackson (2000) stressed on the importance of supporting the family caregivers, and that the home care concept should be holistic incorporating the full needs of

the patient as well as addressing the needs of family caregivers. In some instances family caregivers have died first before the patients that they were caring for due to issues of lack of medical attention, burn out and lack of resources. Issues of attitudes, culture and spirituality for the family caregivers may hinder the quality of care being provided to the patients. In as much as family caregivers provide care to the patients it is imperative to assess their willingness and ability to care, as well as the support they need to enable the role of caring.

2.6 The Use of the Carer Support Needs Assessment Tool (CSNAT)

Ewing *et al* (2012) developed and validated a Carer Support Needs Assessment Tool (CSNAT) which is a systemic way of assessing the needs of caregivers. It has five major steps which when followed will yield information on the impact of caring on family caregivers as well as the form of support needed by the caregiver during the time they will be caring for the patient.

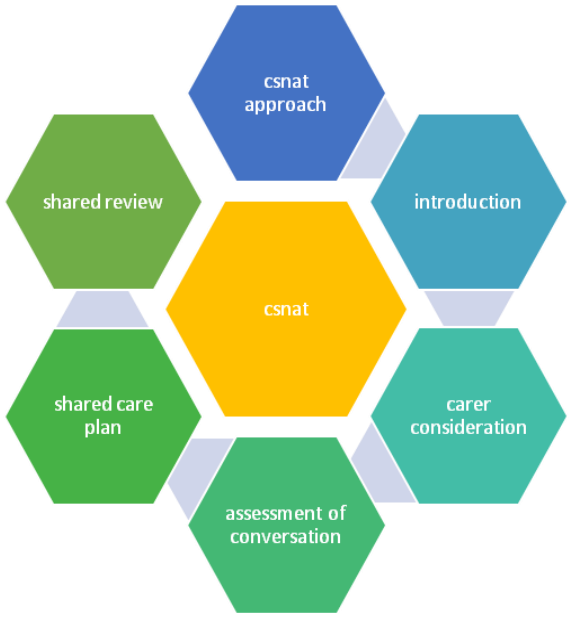

Figure 1: Stages of the CSNAT Tool

2.6.1 Introduction Stage

The introduction stage is the first stage assessment stage when the assessor meets the family caregiver and patient for the first time. After attending to the patient, the family caregiver is also assessed. Questions asked include demographical information followed by relationship to patient. The caregiver will be asked about her/his views towards caring for the patient, feelings and caregiver's needs and support systems. It is during this stage that the assessor will introduce the interdisciplinary team and ask for permission to refer family caregiver appropriately either to social worker or psychologist.

2.6.2 Caregiver Consideration Stage

This is characterized by obtaining patient's information from the family caregiver's perception which includes patient's diagnosis, prognosis condition how they feel about caring for the patient and, what problems they are experiencing in caring for the patient. It is important to create a good working relationship with the caregiver based on honesty and trust. The caregiver is made to understand that he/she can rely on the palliative care team and can call whenever the need arises.

2.6.3 Assessment of Conversation Stage

The assessor and other team members should deduce the meaning of the conversation with the caregiver. However, it is also important to note that each caregiver situation is a unique and cannot be compared as it differs from family circumstances, dynamics and cultural aspects.

However, it is also important to note that each caregiver situation is unique and cannot be compared as it differs from family circumstances, dynamics and cultural aspects. According

to Montgomery and Koloski (2008), there are cultural rules that impose responsibility of care and even if family carers are doing similar tasks it is not possible to assume that they feel in the same way. Everybody has individual needs and reacts to situations in a unique way. When family caregivers receive supportive intervention in tandem with their needs, this will assist in the family caregiver to recognize that they are doing an appropriate job which has the ability to empower the caregiver. Interventions which include provision of home care assistance, support groups, education programs can assist the family caregiver to meet the challenges that could have been causing distress

2.6.4 Shared Care Plan

The patient, family caregiver and patient are to formulate a care plan which is suitable for the caregiver as well, instead of imposing orders and times.

2.6.5 Shared Review

The team has to review the care plan on time determined by the patient's condition as well as caregiver circumstances. As a result this will also promote a better quality of life for the family caregivers as well as the caretaker. Feinberg (2008) asserts that more attention is required to assess the specific needs of family caregivers at different times so as to provide the right support network, taking into cognizance the ever changing nature of family care giving experiences. It is essential then to locate the cause of distress and ways if relieving stress (Montgomery and Kosloski, 2008,). Studies show that in order for the family caregivers to reduce their own distress, it is required to have both skills and knowledge to provide care. According to Sherwood,(2008), many family caregivers say that they do not receive enough guidance from providers on how to assume the caregiver's role, that they do not have the skills and information necessary to provide care and do not know where to

access it and therefore they feel unprepared to care for a person with chronic illness that can lead to a problematic situation since the family carer's wellbeing is often strongly connected to their care situation, how it is interpreted, as a burden or not.

The CSNAT tool is great in assessing the emotional and social needs of the caregivers but it does not assess the practical needs of the family caregivers. In third world countries there is need to assess practical issues which include ability to pay for services, availability of food as well as transport to ferry the patient to the hospital for review.

2.7 Working with Family Caregivers

The family caregivers need information and emotional support from the palliative care team or other health care providers who will be supporting them in providing care. Hudson and Payne (2009) in the guidelines for health and social care professionals reiterated that family caregivers require ongoing information regarding the patient's condition and training on the provision of physical care. As patients approach death, family caregivers and patients experience distress (Kübler-Ross E 1992). Some of the distress will be emanating from the realization of one's own mortality, anticipatory grief, and fear of providing care to a dying patient, guilt about lack of patience in providing care or their failure to notice developing symptoms. However, with counselling and good teamwork, the family members will be supported to have the home-based care patient to die at home through early, sensitive discussion and planning about how best to manage the patient's factors that enhance family caregiver's coping include having an open relationship with the patient and the provision of psychosocial support, as well as provision of information by the palliative care team.

Hu Li Za Zhi (2011) expressed that Challenges faced by family caregivers arise from the burden of care giving resulting in caregivers feeling overwhelmed by their duties. This affects

them emotionally and physical where they end up burnt out. However the caregiver burden may not be apparent to the palliative care team, the end result is the reduction of the quality of care provided to the patient. Therefore the palliative care team should check with the caregivers about their feelings regarding the patient care timorously ensuring the provision of adequate psychosocial support and truthful information to family caregivers. Such information will help them to cope with the situation. Harding, Epiphaniou & Higginson (2012) Caregivers of patients under home care experience lack of resources which affects implementation of care. This leads to patients not having their needs met to ensure quality of life.

2.8 Home Death.

Many patients choose to die at home with some family caregivers prepared to care for the patients until death at home and this choice is supported by palliative care. Research from Europe has shown that patients with advanced cancer would prefer to be at home when they die. Gomes, *et al* (2012) documented that the British have shifted the dying place from hospitals to homes. There is no more stigma attached to home deaths as before where a home death was associated with negligence and poverty. The outcome is quality of death, good quality of death is perceived by some as dying at home in the presents of family members, pain free and not being resuscitated. Schumacher (2008) reiterated that patients want to die at home and end up dying at home, where families require support to cope with the home deaths. Therefore it is crucial for the palliative care interdisciplinary team to provide holistic support to the patients and family caregivers to enhance coping when the patient reaches end of life.

Death happens in different forms. It could be unexpected like in cases of accidents or other medical conditions such as cardiac arrest. It can also be expected such as in patients with life threatening illnesses. In addition the family caregivers feel helpless as they cannot alter the patient's deteriorating condition other than caring for the patient until the time of death. In addition Twycross and Litcher (1998) in their chapter on the terminal phase stressed that "most of the support which the dying person needs can only be given by the family." The family will provide for the patient's needs with the help and support from either the family doctor, community health workers or the palliative care team as well as the community home-based care team.

However, it is not always the case that family caregivers like to provide care to the patient. In some cases the family caregivers may not provide the love and support to the patient at all causing emotional distress to the patient (Twycross and Litcher, 1998). Views about dying at home are mixed, as several questions are raised. Such questions include whether the family caregivers are capable of providing end of life care, whether it is an alternative to hospital care. The other issue is that of how the family views a home death and the impact of a home death on the community. It is high time that death and dying issues are discussed openly so as to expel myths and fears surrounding death particularly home deaths.

2.9 Trajectories of Dying

Glaser and Strauss (1968) referred to the trajectory of dying as a pattern of events that serve as markers of the patient's movement towards the death. This is also a social process created and modified by the decisions and actions taken by the people involved. Death of a patient with a terminal illness can happen at home, in the emergency room, in the intensive care unit or in the ordinary ward.

Bertman (1991) in her book Facing Death, documented that terminally ill patients experience total pain when facing the prospect of their own dying.Even though the non-physical aspect of dying is often overlooked by health professionals as well as family caregivers. The patients experience emotional, spiritual and social pain associated with their demise in silence. Dying patients experience anticipatory grief at the prospect of dying. Part of this pain includes having uncomfortable feelings of loneliness and isolation.

During this period communication between patient and family and medical staff is difficult as the staff and family caregivers avoid talking about painful issues to the patient as they do not want to 'stress' the patient. Saunders in her book Watch with Me (1965) described the pain experienced as emanating from a sense of loss of control, loss of autonomy and vulnerability. This, according to her, leads to a diminished sense of loss of self-esteem and dignity which results in social withdrawal and depression. The spiritual pain experienced emanates from the patient questioning the meaning and purpose of their life, meaning of present suffering and concerned about their relationship with their superior being e.g. God and issues of life after death depending on their belief system. The prospect of dying and losing loved ones as well as everything acquired while in good health can frighten the dying patient. This also depends on what death means to them. The dying patient may also worry about the actual dying itself as they have never died before. Some may feel that they are letting family members down by dying hence the need for permission to go from loved ones.

Poss (1981) in her book Towards Death With Dignity highlighted that since dying is regarded as a life crisis, it therefore demands that the dying be supported as they will be dealing with issues of dying using different coping mechanisms. These, according to Elisabeth Kubler Ross are as follows: There is always shock when one has realised that the disease is not

curable leading to thinking that death is imminent. The person may go into denial where they will be having feelings of disbelief, thinking that the doctor might be wrong. The patient may have anger towards the disease and disease progression, but the anger will be displaced on loved ones with hostility. Guilty and blame is another coping mechanism which can be used where one blames self or the suspected person. The person may also use bargaining where they will be communicating with their superior being e. g. God praying and negotiating for more time and for cure to be found soon. The patient may experience depression at the prospect of dying, feeling useless, as they will be going through all the losses brought about by the condition. Final acceptance or coming to terms with reality is another desired coping mechanism though these coping mechanisms fluctuate as one who would have accepted may go into denial again.

2.10 The Terminal Phase

Kübler Ross (1992) observed that as a patient with incurable disease deteriorates and comes close to death there are physiological changes which happen. This is due to the fact that vital systems will be in the process of shutting down where some specific signs may be observed. Death occurs when the body completes its natural process of shutting down as well as when the spirit completes its natural process of separation from the body.

As death approaches, the spirit of the dying person also begins the final release from the body as well as the immediate environment and all attachments with family members and friends. The spiritual release has its own priorities which may include resolution of whatever is unfinished of a practical nature. The patient detaches self from surroundings and relationships as a way of letting go of the life. The patient may also have decreased social needs where they may prefer few people who are part of his/her inner circle to interact with them. The

patient may speak or claim to be seeing and speaking to people who have already died. The patient may make unusual requests or statements or speak in riddles which are not understood by the family, as an indication that they are willing and ready to die.

Mullick *et al* (2013) define end-of-life as that part of life where a person is living with, and impaired by, an eventually fatal condition, reaches end of life. Quality end-of-life care is realised when strong networks exist between specialist palliative care providers, support care providers and the family work together to meet the needs of the patients requiring care.

African Palliative Care Association (APCA Standards 2010) stipulate that in providing end of life care the palliative care team should involve the patient and family to ensure patient comfort and preserve dignity in dying. The standards express the importance of the palliative care team to identify the signs of approaching death and provide care through management and documentation of distressing symptoms, providing treatment and care based on the patient and family's wishes as well as honestly discussing the end-of-life issues and the anticipation of the death of the patient in a culturally and socially acceptable manner, stress that the main goal in delivering good end of life care is to be able to clarify peoples' wishes, needs and preferences and deliver quality care to meet these needs. Developing an advance care plan for palliative care patients is considered as best practice in the provision of end of life care.

Advance care planning enables the palliative care team to plan for the provision of care as the patient's condition deteriorates, and enhances the provision of quality care for the patient and dignity in dying who has reached end of life. Use of CSNAT will facilitate for discussion with patients and their families and family caregivers about their wishes and thoughts for the future. This discussion is done step by step over a long period of time. It is generally felt that

the experiences though somehow similar cannot be generalized to the African context given the differences in cultural, socio-economic experiences of those who receive palliative care in the West and those who receive it in the developing world. Hinton (1994) recommended that the palliative care team should provide information and support to the family whose patient is dying at home.

2.11 Cultural Issues in Palliative Care

Gire (2002) highlighted that even though end of life experience is universal, the behaviours associated with expressing grief are very much culturally bound. All cultures have developed ways to cope with death in a respectful manner. Interfering with these practices can disrupt people's ability to cope during the grieving process. Religion can be thought of as a cultural system of meaning that helps to solve problems of uncertainty, powerlessness, and scarcity that death creates. In placing death within a religious perspective, bereaved persons find meaning for an event that for many is inexplicable. The mix of cultural or religious attitudes and behaviours surrounding death and dying can become complex. There are different rituals of coping with death and dying as prescribed by different cultures. This includes families' belief on what happens after death, place of death, handling of the body as well as rituals performed to honour the dead. There may be some similarities and differences in cultures regarding the issue of rituals and support.

A study conducted in Zambia by Burnett (1999) revealed that traditional healers in Zambia need more training to enable them to provide counseling to people living with HIV. This will enable them to work with patients requiring palliative care. However, the Xhosa of South Africa view traditional healers as 'contaminated' by death so they often do not provide care to the dying patient. According to Drew *et al* (2000) Shona culture perceives illness and death

as caused by evil spirits though harm can be prevented if there is early involvement of strong spiritual mediums to cure the illness. However, Graham, *et al* (2013) documented the importance of health professionals to be aware of the spiritual and cultural needs of patients and families as they reach end of life and develop appropriate end of life care plan. This practice will yield better outcomes for patients and families.

Cultural practices vary depending on the tribe but generally the concepts are similar. Sickness and other problems are viewed as spiritual problems causes of which are witchcraft, lack of performed rituals and curses. Drew *et al* (2000) highlighted that in Shona practice, a sick patient is taken to a traditional healer who will diagnose cause of illness and give medication to overcome the spirit causing the illness. But if the spirit causing the illness is more powerful then the patient will die. All diseases are perceived as curable and the concept of terminal illness is alien. This affects the palliative care concept, where the patients and their families will not be comfortable to discuss issues of and of life care. This renders them gullible where they may end up wasting resources seeking for a cure. In other instances they will be given wrong information regarding their illness which feeds into their denial. Therefore planning for death is regarded as taboo and not permitted. There is a belief that when one talks about their dying they will be exposing themselves to witchcraft where they will die because they would have invited the death. So when there is a terminal illness in the home the conversations often focus on searching for cure rather than preparing for death. So everything possible should be done to keep the dying alive. Even Will writing is not encouraged as it is believed that by writing a Will one will be exposing self to witchcraft and death. However, culture is dynamic and people are accepting new concepts such as Christian morals and values as well as values for other belief systems. This in a way causes confusion

as well as application of double standards where the family takes the patients to traditional and faith healers secretly by night to avoid being seen by their religious mates. However, the palliative care team gives correct information to enhance autonomy, and patients are supported in whatever decisions they make regarding their treatment and care.

2.12 Conclusion

The chapter has discussed palliative care, the home-based care model and the concept of home death. Cultural issues in palliative care affecting care giving were also discussed. Much focus was paid on the invaluable work of the family caregivers, the use of the CSNAT to assess family caregiver's knowledge, needs and how they can be supported. Issues of death and dying were discussed as well as coping strategies used patients and caregivers feel when faced with death. Throughout the chapter, certain weaknesses of the study of palliative care have been observed; firstly the lack of modern afro-centric literature of this field has compromised the validity and reliability of the information as it cannot be generalized to the local context as it is based mostly on foreign experiences. Secondly the review also highlighted past experiences of palliative care. These are very accurate accounts of how the field has evolved from the past. However, we cannot infer recommendations for current practice based on the information gathered from the review as it may be obsolete. Practices, medicines and policies have evolved from the time some of the articles were published.

Given the above observations it was imperative for the researcher to explore palliative care practices in Zimbabwe as the findings will demonstrate modern trends that are pragmatic and applicable to the African context. The next chapter will present the research methodology used in the study.

2.13 Rationale for the Study

Some family caregivers of patients under Island Hospice care seek help at the emergency unit which results in some patients dying on transit to the emergency unit or in the emergency unit while others may be admitted in hospitals and end up dying in hospitals which would be against their wishes. Therefore, the researcher explored issues influencing the family caregivers to seek help at the emergency unit. The information will assist Island Hospice to formulate new strategies of fully supporting the families to successfully deal with patients at home until the end of life where appropriate.

2. 14 Aim and Objectives of the Study

Aim

To explore and understand issues that influence family caregivers at Island Hospice to seek help at emergency units for patients who are terminally ill.

Specific Objectives of the Study

1. To describe the situations and events that influence families to take or send terminally ill patients to the emergency unit.
2. To explore understanding of end of life care by family caregivers
3. To identify challenges experienced by family caregivers in providing end of life care at home
4. To identify what form of support families would like to have towards the patient's end of life

CHAPTER 3: RESEARCH METHODOLOGY

3.1 Introduction

This Chapter focuses on the approach that was adopted by the researcher in carrying out the study. It includes aspects such as the research design adopted, research instruments, data collection methods, sampling methods, the target population and presentation and analysis procedures. Prominence is given to the qualitative methodology due to its exploratory nature and its capability to explore frames of family caregivers and how they are coping with the patients in their homes. According to Denzin and Lincoln (2008) qualitative research methodology allows the production of data based on a number of methods such as key informant interviews, in-depth interviews, and observation. This was a mixture of phenomenology and ethnography, in the sense that phenomenology is about individual experiences even though the individuals were having same situations but had different perceptions and different coping mechanisms. In ethnography the purpose was to explore how respondents' different ways of life affected the care provided, and the decisions they made, realising that culture is dynamic and people of the same ethnic group may not make the same decisions given the same circumstances. These methods are employed in this study so as to secure an in-depth understanding of the issue under investigation

3.2 Research Design

This was a descriptive qualitative study. It was designed as a phenomenological and ethnological study to explore the lived experience of family members of patients cared for by Island Hospice through qualitative analysis of data derived from participants' narratives.

3.3 Study Site

The study was carried out at the family homes in Harare and Chitungwiza. This study site was chosen because palliative care services through Island Hospice have been available in these areas since 1979.

3.4 Study Population

The study population consisted of family caregivers of terminally-ill patients who attended emergency unit at Parirenyatwa Central Hospital or the Chitungwiza District Hospital during the first nine of months 2015.

3.5 Selection Criteria

The study focused on adult family caregivers who are the main carers of Island Hospice patients who presented to the emergency unit during the January to September 2015 period.

3.6 Sampling

A purposive sampling of Island Hospice clients whose patients attended the emergency unit was used for this study. The sample size was determined as between 12 to 16 participants or until data saturation was reached

3.7 Data Collection Tools

A semi-structured interview guide was developed after discussing with the supervisor during the tutorials. This was influenced by the experiences the researcher had of patients and families cared for by Island Hospice. It was developed in consultation with colleagues and the study supervisor. The researcher translated the interview guide to Shona and shared the tool with Shona speaking colleagues to ensure that meanings of words are not lost in

translations. The researcher wanted to investigate issues that influence family caregivers to take patients on the Island Hospice palliative care programme to emergency rooms

Pre-testing of the tool was done prior to conducting the study. The pretesting was done by purposively selecting two family caregivers from Harare, who were visited and interviewed in their homes. The reason for pre-testing the instruments was for the investigator to identify and eliminate any potential problems such as questions that may be misunderstood by respondents. It allowed the researcher to make appropriate adjustments to the tools to ensure that the required data will be captured.

3.8 Recruitment of Participants

The researcher met with the clinical teams' manager of Island Hospice who arranged for a meeting with the two community home care team leaders and a social worker of Island Hospice where the study was introduced. The home care team leaders were informed of the research process and asked to assist by identifying and referring the family caregivers who had taken patients to the emergency rooms in the last 9 months from the beginning of March 2015 to the end of December 2015 to the researcher. The Island Hospice staff communicated with the potential participants about research and provided the researcher with home addresses. The researcher then visited the participants at their respective homes explaining the purpose of the study and sought their consent prior to conducting the study.

Informed consent was sought from the respondents before they agreed to participate in the study. Full information was provided in the potential participant's language of choice and potential participants were given the opportunity to ask questions about the research and participation was voluntary. It was clearly explained that there would be no remuneration for taking part in the study and that the study was for academic purposes. This was so that no

expectations of payment would be held considering the context of poverty in Zimbabwe and no perverse incentive offered for taking part in the study to ensure voluntary informed consent. All the information provided by the respondents was kept in strict confidence. Anonymity of participants' identity was achieved through the use of pseudonyms. The participants signed informed consent documents.

3.9 Data Collection Process

The researcher conducted the audio recorded interviews in Shona using the semi-structured interview guide which was developed prior to the study. An audio tape was used to record, and a notebook was used to capture field notes, document events and observations made during the data collection process. The data was collected at the participants' individual homes. When conducting the interviews, the researcher was objective and systematic in order to reduce own biases which may affect the interview process. The interviews were recorded, transcribed verbatim and translated to English after every interview. The researcher is fluent in both Shona and English and a colleague also fluent in Shona and English checked the English transcriptions against the Shona recordings of the respondents, to make sure that nothing was lost in the translation. The advantages of using a recorder were that the researcher could playback and transcribe making sure that no information was left out, and the interviews were stored to be played back later for validation (Gerrish 2009).

3.10 Distress Protocol

The protocol for managing distress in the context of this research was put in place where a social worker was on standby. Participants were informed about the protocol which clearly stipulated that if the participants became emotionally involved, then the interview will be stopped immediately and involve a social worker to provide counselling, if the participant

wanted this assistance. The interview would either be discontinued or postponed to a later date or would be cancelled completely depending on the wishes of the participant. The researcher requested for a Hospice social worker to be available to provide additional emotional support to participants if the interview resulted in emotional distress. There were no respondents who became emotionally distressed during the data collection.

3.11 Data Storage and Confidentiality

Data was coded using pseudo names in order to maintain the principle of confidentiality. Audio tapes were to be kept securely locked away in a locked filing cabinet that was only accessed by the investigator. After transcription of the interview and checking for accuracy, the audio tapes were destroyed. Hard copy transcriptions were kept in a locked cabinet in the research office.

3.12 Data Analysis

The data analysis approach was done systematically using a step by step manner as described by Terre Blanche (1999). After recording, each interview was transcribed verbatim. The initial transcription was in the Shona language then the recordings and transcriptions were reviewed twice before being translated to the English language. After transcribing the data, and checking the translations, to deduce meanings of words, as the Shona language has same words which mean different things, the data was then coded according to themes.

This was followed by familiarisation with the data through immersion in transcripts where the transcripts were read and reread in order to become familiar with the content. During the reading of the transcripts, the researcher refrained from categorising or commenting on the data to minimise personal influence on the analysis. The researcher became sufficiently

familiar with the transcripts and data to know where in the transcripts specific data are found and once the themes had been identified, data supporting the themes or conflicting with the themes could be utilised. The main issues emerging from the text were identified. Familiarity with the data allowed induction of the principles underlying the data. During this phase, the researcher reread the transcripts making notes and drawing diagrams which formed an initial grouping of similar topics and these groupings were refined as data analysis progressed.

Key phrases in the texts were highlighted using different coloured highlighters and these verbatim phrases were cut out and stuck onto cards, clustering the issues with similar content. The cards were labelled with headings directly describing the content. The phrases were coded to identify which interviews they had been taken from.

The cards were used to identify categories as groups of issues and to formulate themes in order to answer the research question. This allowed a flexible organisation of data supporting the developing themes. Common properties in the initial categories pointed towards links in categories that supported grouping these categories into the emerging themes and sub-themes.

The findings of the study were presented in a thematic approach where recurring themes in the study were identified and presented. Data that appeared to relate to different sub-themes were further compared and analysed to identify the data most relevant to each theme. The initial induction of themes following the analysis of focus group data was refined by constant comparison with the themes emerging from the individual interviews. The process of constant comparison resulted in exploring themes more fully and revising the analysis until the structure described the results in a coherent and valid form.

During the process of data analysis, a conceptual framework developed which was influenced by observation and listening in the interview process. A sense of the family care givers'

willingness to care for patients at home the lessons and challenges they experienced through their caring journey, as well as factors influencing their decision to send patients to the emergency unit affected the researcher.

In the process of data analysis, the effect of the researcher is acknowledged (Malterud 2001). Reflexivity is maintained by looking at the data for competing conclusions. During all the steps of the research, the effect of the researcher was assessed.

The choice of research instruments where semi-structured interviews were used. The exploration of individual views was enhanced by the method.

3.13 Ethical Considerations

Ethical approval was provided by the University of Cape Town, Human Research Ethics Committee (HREC) and the Medical Research Council of Zimbabwe (MRCZ). Before the study was conducted, a letter of permission was obtained from Island Hospice.

All participants were fully informed as to the nature of the issues to be in the interview. There were no respondents who became emotionally distressed. The investigator translated the interview guide to Shona and shared the tool with Shona speaking colleagues to ensure that meanings of words are not lost in translations. Data was coded using pseudo names in order to maintain the principle of confidentiality. Audio tapes were kept securely locked away in a locked filing cabinet that was only accessed by the investigator After transcription of the interview and checking for accuracy, the audiotapes were be destroyed. Hard copy transcriptions were kept in a locked cabinet in the research office.

CHAPTER 4: RESULTS

4.1 Introduction

The aim of this chapter is to present and analyse gathered research data, which highlights the study's findings. The demographics and characteristics of the respondents are discussed first to give a clear background so that opinions made can be understood in their perspective.

4.2 Sample Characteristics

A total of 15 respondents were interviewed in the Shona language by the researcher using semi-structured interview guide. All the 15 participants were willing to participate in the study where they signed informed consent forms prior to commencing their interviews.

4.3 Demographic Information

Table 1: Distribution of Respondents by Gender, Age and Relationship

Caregiver	Gender	Age	Relationship to patient
1	Male	57 years old	Husband
2	Female	66 years old	Mother
3	Female	52years old	Wife
4	Male	67 years old	Husband
5	Female	57 years old	Sister
6	Female	53 years old	Sister
7	Female	57 years old	Mother
8	Female	65 years old	Mother
9	Female	59 years old	Mother
10	Female	60 years old	Mother

11	Female	54 years old	Mother
12	Female	54 years old	Wife
13	Female	54 years old	Wife
14	Female	64 years old	Wife
15	Female	56 years old	Wife

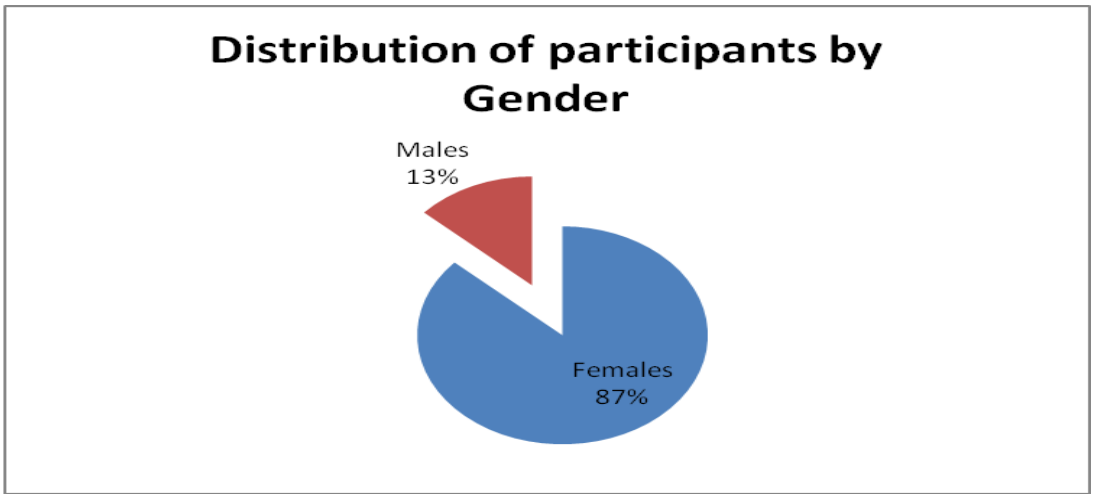

Figure 2: Distribution of Participants by Gender

A greater proportion of the patients being cared for had malignancies some of which were HIV-related malignancies and few had HIV. All the patients with HIV were on antiretroviral therapy and were accessing the antiretroviral medications from different centres which include hospitals and municipal clinics

Table 2 shows data of patients and the different diagnoses of the patient being cared for by the respondents.

Table 2: Distribution of Patients by Diagnosis

Diagnosis	Frequency	Percentage (%)
HIV and Cancer	5	33.3
HIV	2	13.3
Different Cancers	8	53.3
Total	15	100

From the above table it can be noted that the majority (53.3%) of the patients had cancer, followed by 33% of the patients who had HIV and cancer.

4.4 Identified Themes

Following thematic analysis, the results of the research were put into the factors that influence family caregivers to send patients to emergency rooms were categorised into 5 main themes as inserted on table below.

Table 3: Table of Themes

THEME ONE	THEME TWO	THEME THREE	THEME FOUR	THEME FIVE
Caregivers knowledge	Lack of Resources	Psychosocial issues	Physical	Spiritual and cultural issues
1.1 Patient's diagnosis	2.1 Lack of medications	3.1 Fears	4.1 Burnout	5.1 Belief in witchcraft
1.2 practical caring skills	2. health professionals strike	3.2 Poor communication with the palliative care team	4.2 Aches and pains	5.2. Traditional and faith healers
1.3 Pain and symptom management	2.3 Lack of housing	3.3 Family dynamics		5.3 Stigma and discrimination by church members
1.4 Dying process	2.4 Lack of funds	3.4 Issues of sexuality		

THEME ONE

4.4.1. Caregivers' Knowledge

4.4.1.1 Caregivers' Knowledge of the Patient's Diagnosis

The respondents caring for patients with HIV and AIDS were knowledgeable about the diagnosis of their patients. The patients had disclosed their statuses to their family caregivers. Disclosure is not much of an issue due to the availability of antiretroviral therapy since patients are encouraged to disclose their HIV status as part of the antiretroviral therapy management plan.

"I am so worried about why he is not getting better yet he is taking ARVs. We were made to understand that ARVs prolong life. Does it mean that I will also end up like him?" Participant 7.

Meanwhile the respondents, who had patients with a cancer diagnosis, had some knowledge of the diagnosis of their patients though some were not aware of the implications.

"Doctors informed us that the cancer has advanced, but I feel that if they remove the cancer he will be fine. He is the only one with cancer in his family we do not know where it came from." Participant 5

"We have relatives in the UK who are willing to fund his treatment because we are not on medical aid. I know that some of the cancer medicines are not available in this country. But what matters to us is to have him treated." Participant 6

4.4.1.2 Lack of Caring Skills

Most of the respondents reported that they were experiencing challenges in providing physical care for bedridden patients who were helpless. Procedures like bed bathing, feeding, turning and providing oral hygiene to the patient were daunting as the family caregivers did not have practical caring skills as this was their first experience.

"We had to ask for his niece to come and help with providing care to the patient since he is bedridden. Turning him was a problem for me and I now suffer from backache as a result of turning him on my own". Participant 4

"I was taught how to bath mum in bed and it has helped me a lot because I used to carry her to the bathroom but now it's easier for me." Participant 12

4.4.1.3 Distressing Symptoms

The distressing pain and symptom spectrum where caregivers felt helpless made them send patient to the emergency unit.

"My husband was vomiting blood prompting us to take him to the hospital." Participant 8

One respondent caring for her husband took him to the emergency unit for pain management.

"My husband's pain was being managed by cocodamol every four hours. But somehow on this particular day he complained that the pain was getting worse, I gave him 2 cocodamol tablets but the tablets did not stop the pain. He began to shiver and he was groaning. I decided to take him to hospital at that stage because I felt that I could not help him on my own. I did not call Island Hospice because I did not have the $25 they require for consultation. The difference with hospital is that consultation is $10.00 and a patient can be

admitted and the family will pay the hospital bill later. He was given a morphine injection and some morphine tablets and sent home to be cared for by Island Hospice." Participant 14

4.4.1.4 The Process of Dying

A family caregiver caring for her mother felt the illness was getting worse prompting her to seek help at the emergency unit.

"She became profoundly weak and was drowsy for extended periods, was not eating and I felt unable to care for her at home. I knew that if I took her to hospital, they would put up a drip and feed her through the tubes. It is better than leaving her to die of hunger. The Island Hospice team had prepared me that she was going to die. But the challenge is that they come and go leaving you alone to care for the patient. The other relatives are in the rural areas and with no cash these days it is difficult for them to visit frequently." So I hired a vehicle from a neighbour to take her to the hospital. The ambulance is expensive moreover it is expensive whereas my neighbour charged me a reasonable amount." Participant 15

One respondent whose husband died in the emergency room was happy that the patient died away from home.

"He died soon after arrival at the emergency unit. I was relieved that he did not suffer much; they tried to resuscitate him but in vain. Umm the thing which gave me peace was that he died away from home. You know his family members would have accused me of neglecting him and secondly his spirit is safe away from home otherwise the children would have refused to live in this house fearing that it will be haunted. If he had died at home then we would involve traditional healers to cleanse the house." Participant 2

"Because of the knowledge I received from Island Hospice I now understand the patient better, have improved my communication with patient and am able to manage the pain by giving pain medication regularly to the patient. It is now easy for me to bath and lift the patient correctly without causing harm to patient. The medical equipment which they gave us improves the quality of care for the patient in the home setting." Participant 3

THEME TWO

4.4.2. Lack of Resources

Lack of resources across the board being financial, material and human was another theme. . Most of the cancer patients did not receive comprehensive cancer treatments due to lack of resources. Some of the patients did not go for surgery as they could not afford the medical bills required for them to have the necessary operations. Fifty per cent of the patients did not have radiotherapy or chemotherapy and the sited lack of resources as the reason for not having the required treatments

4.4.2.1 Lack of Medications

"My son needed chemotherapy but it was not available at the Hospital, so we tried the Cancer Centre but they also did not have the drug. We sent to a neighbour's son who said he will buy the drug when he gets the money but he never sent the drug. This makes me angry to think that the medicines which are needed are not available. I do not know what will become to all of us in this country." Participant 11

"There was no morphine at Island Hospice and at all the pharmacies that we approached. The pharmacists kept referring us to other pharmacies in search for the morphine but in vain.

So we took James to the hospital where he was admitted. I heard that they were injecting him in the morning and evening because the morphine tablets were out of stock. He was finally discharged after five days and morphine tablets were in stock. I heard that they were donated. Lack of medicines affects the quality of care for the patient, as he was in a lot of pain and I could not bear to see him suffering like that." Participant 1

"*Island Hospice visits are not consistent as there are days when they are not visible. Moreover Island Hospice staff is not available in the evenings and during the night when the patients are suffering more and screaming due to pain, over and above that Island Hospice also charges for their service which made me reluctant to call them as this has cost implications for the family when we are already struggling like this. Island Hospice should improve their services and coverage as well as extending to rural areas***"** Participant 12

4.4.2.2 Staff Shortages

The issue of industrial action by health professionals resulted in having no staff to attend to patients.

The respondent whose husband was vomiting blood mentioned the strike by health professionals.

"Unfortunately, nothing was done at the emergency unit as the doctors and nurses were on strike, so we brought the patient back home. The second time he went to the hospital he spent the night without being given medication by the nurses who said they were waiting for a consultant to come and see him. The following morning he asked to be discharged as he felt that they did not care about him." Participant 8

Another respondent bemoaned the disappearance of blood results from the laboratory

"When I took him for review we were informed that the blood results were not found. It was suspected that the results were mixed up during the strike by health professional as they were operating on skeleton staff. Most health professionals are working out of the country for better conditions of service. This leaves us to suffer and the country's leaders also go out of the country for health care while we who have no money suffer". Participant 9

4.4.2.3 Lack of Housing

Lack of housing was mentioned as one of the reasons for taking patients to the emergency rooms where the family members were hoping that the patients will be admitted.

"My landlord said their house is not a hospital where patients are admitted and also said we should limit the number of visitors. This made it very difficult for me to inform some of the relatives about the illness. So hospital was the most suitable option for us" Participant 7

"It's not easy to provide care to a chronically ill patient at home when you do not have your own house. Two landlords gave me notice to vacate when they realised that I am looking after my sick child. I cannot go to the rural areas because there is no care there whatsoever. So how I deal with the situation is that I take him to hospital for possible admission when he is not well. Island Hospice social workers said they could not help us to get a house" Participant 9

Lack of tap water also made it difficult for the caregivers to uphold the principles of hygiene in providing home care. *"I have to fetch water from the communal borehole where there will be a long queue depriving me of time to spend with the patient. Sometimes if there are kind people in the queue who know of my predicament they make me jump the queue and*

neighbours sometimes give us a bucket of water. I have to be careful of how I use that water in case it gets finished and I have to go to the borehole twice". Participant 4

4.4.2.4 Lack of Funds

Issues of poverty were highlighted by most respondents as the economic situation of the country is not stable.

"There was no food in the house he does not want to eat vegetables only with no meat. I had no cash to buy food since I was no longer going to the market. I felt that if I take him to hospital at least he will be given a well balanced diet. The Island Hospice staff only gives medications without giving food packs. Moreover they are now charging $25 per visit. Of course they claim that they can see you for free but the fact that they want money makes one to think twice before calling them. Their charges are too high who can afford $25? Hospital is better because they charge $10 and if patient gets admitted, one can pay the rest in instalments. The social services is no longer offering assisted medical services, they have run out of funds. Imagine many people are out of employment so the burden is huge." Participant 2.

THEME THREE

4.4.3 Psychosocial Issues

Provision of psychosocial support when it was needed in most instances was lacking which made some respondents to take patients to the emergency rooms.

4.4.3.1 Fears Some of the respondents described the symptoms being experienced by family members as frightening.

"She was breathing in a funny way, she had tears rolling down her eyes, I had never experienced that before, so I decided to take her to the emergency rooms at least she was going to be cared for by professionals.". Participant 15

4.4.3.2. Poor Communication with the Palliative Care Team

The palliative care team members do not visit regularly due to lack of resources and shortage of staff. This leaves the patients and caregivers feeling isolated and neglected.

"When the nurse visited, we talked about the patient's condition and I verbalised my concerns, I felt some relief though not entirely satisfied, I would have wanted another session. Then two days down the line his condition deteriorated further, I did not call Island Hospice but decided to take the patient to the emergency unit where I was expecting to have an opportunity to talk to the nurses and doctors at the hospital about my concerns". Participant 1

4.4.3.3 Family Dynamics

Pressure from visiting relatives affected family caregivers, as well as family fragmentation which resulted in family caregivers feeling isolated. .

"His family members came at the last moment and failed to deal with the fact that he had deteriorated so much. They brought the money so they could give orders to take him to hospital. I had no voice and moreover he is their relative and they wanted him admitted Participant 7

"His family were pressurising me to send him to hospital because they thought we were neglecting him. We strategized that if we take him to the emergency rooms during the night hours, he will be admitted. So we took him at around nine o'clock at night and he was admitted." Participant 2

"This man never loved me when he was well, and he was enjoying his money alone with girlfriends. But now I have to care for him and my back is aching from lifting and turning him. His nephew came from the rural areas for a month and quickly returned leaving me to deal with him alone. I only have daughters and they are both married. The one who lives in Kwekwe is supportive but she only comes occasionally and moreover she cannot bath her father. I wish he can be admitted in hospital for a long time." Participant 10

4.4.3.4 Issues of Sexuality

Sexuality issues among palliative care patients are viewed with contempt as others believe that patients have no right to conjugal rights. When exploring fears among the partners whose spouses are ill most of them express fears of the spouse dying during the act. Some fear being infected even if the spouse does not have HIV or sexually transmitted infections. Moreover culturally if a man who has been ill asks for conjugal rights, it is viewed as a good sign of recovery.

"Can you imagine that my husband demanded for sex in that condition? He was angry with me when I refused and he told me that he had paid lobola (dowry) for me therefore I was obliged to indulge at his request as he was my husband. Though we did not indulge, I felt very guilty that I had let him down as my husband. But my husband has not recovered yet instead he is getting worse. I was scared and felt that he was not healthy enough to indulge in sexual activities." Participant 15

THEME FOUR

4.4.4. Physical Issues

Some family caregivers highlighted that they were feeling tired of caring for the patients. They also needed time to nurture themselves.

4.4.4.1 Burnout

Twelve respondents mentioned that they were experiencing signs of burnout, and they could not cope with caring for the patient at some point during the patient's illness.

*"I became so tired that I wished somebody could take over the caring responsibility from me. I could not concentrate on what I was doing and I would feel angry whenever he called for help. I would cry in private and I hated myself for feeling like that"*Participant 8

I was almost run over by a bicycle when I was coming from the shops. The bicycle rider verbally abused me that I was confused as I did not look at where I was going. Fortunately I was not injured; I just sustained a bruise on my right knee. Now I dread going to the shops so I send a neighbour's son" Participant 12

4.4.4.2 Aches and Pains

"My body is aching everywhere; I know it from lifting the patient. But there is no one else to do it. Am thinking of sending him to hospital again so that I can rest, but the problem with him being admitted is that he will come back with bed sores from the hospital. The hospital staff does not really care for helpless patients "

"My back is sore from lifting; I wish somebody could help me. Hospice does not provide hands on care, they visit but they do not help with bathing and changing patients. Of course

they teach us caring skills but sometimes one needs to be helped I cannot afford nurse aide as they have to be paid, The community home based volunteer does not visit every day but she is helpful when she comes" .

THEME FIVE

4.4.5 Spiritual and Cultural Issues

The belief in witchcraft was perpetuated by the desire to protect patients from being bewitched. Families who consult traditional healers also take patients to the hospitals the families involved in this practice see nothing wrong in mixing traditional and conventional medicine.

4.4.5.1 Belief in Witchcraft

There is a myth that when a patient is very ill and is being nursed at home, the witches will facilitate death as they are said to eat dead bodies. So as a result of this myth caregivers send patients to hospitals as a way of protecting them and preventing their death.

"We sent her to hospital as a way from preventing the witches to continue bewitching her so we lied to visitors who came home to visit her that she had gone to the rural areas. At least she was better by the time she came from hospital" Participant 15

4.4.5.2 Traditional Healers

Some respondents believe in the healing powers of traditional healers as they are said to have mystic powers and communicate with the individual's dead ancestors. There is lack of resources such as medications for symptom management in the health services, some patients seek help from traditional and faith healers as a result. Moreover traditional and faith healers

do not charge much for treatment in a country where medications are either out of stock or unaffordable. Some of the traditional healers remove objects from their patients which are perceived as having been inserted by enemies through witchcraft.

"The following morning he asked to be discharged as he felt that they did not care about him. In both instances since the situation was serious we resorted to traditional healers, who gave him traditional medication which helped a lot as the vomiting stopped." Participant 8

"Way back, my husband was very ill, the traditional healer informed us that he had been poisoned at the beer hall, by his colleagues who hated him. The colleagues attempted to kill him on several occasions, as he had been promoted to a senior rank. He was given herbal concoctions and he vomited the poison. This time they have successfully bewitched him. His relatives do not want him to take conventional medications, as they were instructed by the traditional healers not to mix traditional and conventional medicine which they believe will harm the patient. But when I took him to the emergency unit behind their back he felt much better." Participant 1

4.4.5.3 Stigma and Discrimination by Church Members

Some church members do not understand that some conditions are not curable even after praying and fasting regularly. Some patients and caregivers were labelled as not having enough faith to receive their healing.

"They used to visit and pray with us at the time of diagnosis, during that time the patient would receive communion at home. But now that the disease has taken a long time with the patient deteriorating but not dying, they stopped coming. Some members are even accusing me of not attending and supporting church as if they do not know that I am looking after a

patient at home. This treatment by church mates has affected me so much that I will never go to that church again". Participant 13

"*The landlord told us to vacate as their house was not a hospital. Visitors were also limited as they said they were wasting resources in the form of water and electricity*

CHAPTER 5: DISCUSSION

5.1 Introduction

In this chapter research findings are going to be discussed in relationship to the theory and review of the relevant literature. The aim of the qualitative study was to explore and understand issues that influence family caregivers at Island Hospice to go and seek help at emergency units for patients who are terminally ill. Fifteen adult caregivers of both sexes participated in the study. The majority of the family caregivers who participated in the study were women. This further cements long held assumptions that the burden of caring for the chronically sick lies largely in the hands of women Long *et al* (1984). For most of the care givers it was distressing to witness the patient suffering at home with no medications and no consistent support from the palliative care team

5.2 Care Provided by Island Hospice

All participants interviewed felt that Island Hospice offers services needed by the community and there was room for improving the service. Some respondents spoke about advantages of having patients being under the care of the Island Hospice palliative care team in that it helped in the reduction of expenses such as the cost of hiring vehicles to ferry the patient to the hospital and the hospital bills incurred when patient is admitted in hospital. Others did not like the idea of paying for services rendered and identified problems with availability of Island Hospice team. They felt the services were not readily accessible as the Island Hospice team does not visit daily, exposing the family to the pain of dealing with the progressive decline of the patient on their own. The sad situation resulted where the caregiver would be

alone with patient without visible support from Island Hospice team, created panic and anxiety among the family caregivers, who felt they did not know what to do on their own.

5.3 Caregiver Knowledge

When the family caregivers were referred to Island Hospice, they had some knowledge of their patients' diagnosis though they were failing to come to terms with cancer, unlike the HIV diagnosis. Most did not have information regarding how to care for a patient but with the information received from Island, they were able to provide care. They also expressed that they did not have enough support from the palliative care team as the Island team members were not readily available when they were needed after working hours and during the night and many families could not afford the cost charged by Island Hospice. This made it difficult for the family caregivers to cope with managing the pain and other distressing symptoms. The caregivers would be gripped with various fears as they would think that the patient would die in the house suffering from excruciating pain or other distressing symptoms. To this end one may note that the findings of this study concurs with the findings of Joanne et al (1997) which concluded that family caregivers find it difficult to cope with a patient dying at home, thus they go to the emergency unit. Most respondents did not talk about death except for the two whose family members had died. This could be due to the fact that most cultures find it difficult to talk about death and dying, though Hospice and palliative care have assisted in addressing these issues in the western world. Emanuel et al (2004) documented that most patients do not feel stressed about talking about their death. However it is the assumption that patients will become distressed that leads health professionals not to talk about death and dying. This avoidance was alluded to by Drew (2000) who highlighted

that in Shona practice, all diseases are perceived as curable and the concept of terminal illness is alien. Therefore planning and even talking about death is regarded as taboo and not permitted. There is a belief that when a person talks about their dying they will be exposing themselves to witchcraft where they will die because they would have invited the death. So when there is a terminal illness in the home the conversations often focus on searching for cure rather than preparing for death. The impending death of a family member creates fear among the family so everything possible should be done to keep the dying alive. Twycross and Litcher (1998) in their chapter on the terminal phase stressed that most of the support which the dying person needs can only be given by the family. However, all respondents expressed that the care and support provided by hospice was good though there was some criticism of Island Hospice. Even though some families appreciated the medical equipment, other family caregivers are disliked the use of medical equipment in the home setting as they felt that medical equipment is for hospitals not homes.

5.4 Practical Constraints

Most of the responses given by participants related to the country's health delivery system. The national strike by all health professionals resulted in patients not being attended to, some patients died, others lost the laboratory results, while others missed their medical reviews and surgical procedures had to be cancelled. Lack of chemotherapy drugs and other palliative care medications affected care delivery. Lack of resources was universal among all the respondents as they were not formally employed. Some depended on family and friends in the Diaspora for financial support though the support was not consistent.

Lack of practical resources in terms of finances where the families were unable to provide for the patients needs, prompted them to send patients to the emergency unit where they hoped that the patient would be admitted in hospital where they would be fed with a well balanced diet. The social services does not provide public assistance as the funds allocated to the department are not enough to cater for needs of patients. Most respondents are not formally employed while some have left their markets to provide care and unavailability of cash to buy suitable food to give to the patients who will be requesting for special food which the family cannot afford to buy distresses the caregivers.

5.5 Psychosocial Issues

The caregivers had no support or no one to communicate with regarding the patient's poor condition making them feel lonely. Some felt that the symptoms being experienced by patients were beyond their scope of coping, while others shared that they had difficulty in providing care as they were not trained to care for the advanced physical symptoms of the disease. They felt the illness was getting worse prompting them to seek help at the emergency unit. Secondly family caregivers did not have enough support from the palliative care team as the team members were not readily available when they were needed after working hours and during the night. This made it difficult for the family caregivers to cope with managing the pain and other distressing symptoms.

The caregivers would be gripped with various fears as they would think that the patient would die in the house suffering from excruciating pain or other distressing symptoms. To this end one may note that the findings of this study concurs with Doyle 2003) who documented that in domiciliary care family caregivers find it difficult to cope with a patient

dying at home, the support from the palliative care team is viewed as never enough, thus they go for emergency unit. Some of the responses given by participant highlighted that the patients themselves requested to be taken to the emergency unit as their symptoms were not relieved at home. The protocol for Island Hospice is that family caregivers are given instructions that they should inform the Island Hospice nurse on call or their usual nurse when the patient has developed new symptoms or when condition has deteriorated. The nurse on call will be in possession of the Island Hospice mobile phone. So the nurse should go and assess the patient and manage the symptoms and communicate with the family. In cases where the nurse on call fails to manage the symptoms the next stage would be to refer to the Island Hospice doctor who will also visit the patient to assess and manage the symptoms.

The respondents expressed that the Island Hospice team does not visit at night thereby creating a gap which results in families sending patients to the emergency rooms.

5.6 Family Pressure

Some of the caregivers feared being blamed by relatives and friends for not taking patients to hospital. The uncertainty of the prognosis placed a huge burden on the family caregivers who in most cases were not residing with the patient. The respondents sought help from the emergency unit as they preferred the intervention given at the emergency unit where in some instances patients are commenced on intravenous infusions which 'revive' the patients. They also hoped that by seeking help at the emergency unit it would result in the patients being admitted in hospitals. The strategy mostly used was to take the patients to the emergency unit during the night as they were assured of admission. The other advantage verbalised was that

having a patient admitted in hospital would afford the family caregivers some respite. Jackson (2000) emphasised that the needs of the family caregivers are usually neglected, while full attention is focused on the patients only which leads to caregiver burnout due to lack of support. In this study a concern was raised that instead of primary caregivers being supported they are mistreated by relatives instead of receiving support. The idea of admitting the patient has a disadvantage of giving false hope to the family which destroys all the work done by the palliative care team in preparing the patient and carer.

5.7 Burden of Care

The social challenges emanated from having poor relationships with extended family members as well as step-children. The respondents found it difficult to cope with the patients' emotions especially where anger was used as a coping mechanism by the patients. The hostile behaviour displayed by patients made the caregivers feel helpless and unappreciated. These were among the challenges raised, as they did not get relieved from the daily burden of caring. This also led to social isolation where one would not be able to attend even church service as they will be caring for the patient at home. Some of the caregivers experienced signs of depression during their long tenure of caring for the patients at home. Other caregivers sent the patients during the night hoping that they would be admitted in hospital, thereby affording them time to rest from caring for the patients. They could not cope with the huge demands placed on them by providing care. They expressed the emotional pain and humiliation of witnessing a relative deteriorating. Fears experienced by family caregivers included fear of the unknown, fear of being blamed for neglecting a patient and fear of stigmatization that a person died in the house instead of dying in hospital. Others feared being

unable to provide proper care while the fear of not knowing how to handle the emotions of patients or how to communicate with the patient had prompted the family caregivers to send the patients to the emergency unit.

5.8 Impact on Caregivers

Caregivers were also affected as they had to deal with losses being experienced by patients. This was compounded by the deteriorating health delivery system where there no medications in the country, resulting in patients suffering from pain and other distressing symptoms. Some caregivers were in poverty due to the fact that some had abandoned their daily jobs in order to provide care to the patients which resulted in them experiencing social and emotional pain due the losses. The plight of caregivers who are lodgers is aggravated by the fact that they are expected to do extra jobs where they live. The caregivers who are lodgers take weekly turns in cleaning the houses where they are lodging. This is a requirement by the landlords that lodgers clean the yard, veranda, passage and toilet for the house where they are lodging. This task should be done early in the morning by 5 o'clock in the morning. These weekly duties were a challenge as the respondents were not able to perform the duties due to the demands from the patients. This also paused a high risk for the lodgers to be evicted from the houses where they will be lodging.

The findings of this study cement the sentiments echoed by Kinsella (2000) that home-based palliative caregivers are at high risk of being affected physically and psychologically which will affect the whole family unit including the patient. This however affects the quality of care given to the patient. This further cements the findings of Jackson (2000) who emphasised that the needs of the family caregivers are usually neglected, while full attention

is focused on the patients only, which leads to caregiver burnout due to lack of support. As described above, this study revealed that instead of supporting primary caregivers, they are being mistreated by relatives. Challenges faced by caregivers were holistic affecting all the domains of their lives. The emotional challenges were caused by fears arising from the caring role and compounded by lack of adequate emotional support from the palliative care team. Failure to communicate effectively with the patient was verbalized by some respondents. Others had issues of sexuality which needed addressing. This is consistent with the findings by Hu Li Za Zhi (2011) expressed that challenges faced by family caregivers arise from the burden of care giving resulting in caregivers feeling overwhelmed by their duties. This affects them emotionally and physical where they end up burnt out. However the caregiver burden may not be apparent to the palliative care team, the end result is the reduction of the quality of care provided to the patient. Some had challenges emanating from being blamed of witchcraft by extended family members

5.9 Caregiver Support

The CSNAT approach which is used as guideline to support family caregivers has yielded good results where caregivers bring given individualised total care. The services offered by the Island Hospice team support the family caregiver in many ways such as giving information regarding caring skills, explanation of meaning of new symptoms as well as how to give medications and communicate with the patients. The difference is that in some countries patients are visited daily O'Connor et al (2009). However Island Hospice does not visit daily and sometimes they do not have medications. McLaughlin et al (2007) documented that with the help of the palliative care team, the caregivers believed that the fulfilment of their loved ones' wish to die at home was enabled by the support and care they received from

Hospice at Home services. In this study all cases interviewed the primary carer was left with the burden of caring and looking for financial assistance, the case was worse when the patient was a spouse, as other family members would distance themselves. Due to the burden of caring worsened by unsupportive relatives some spouses find the burden too heavy to carry.

The family caregivers need constant home visits by the palliative care team as a way of supervising and supporting the caring work they are doing. The family caregivers would like twenty-four hour coverage daily by Island Hospice as they felt it would help to alleviate their anxieties knowing that they can call on Island Hospice at anytime. Lending of medical equipment to home care patients as well as having training on how to care for the patients would be an added comfort for patients. Provision of psychosocial support in the form of ongoing counselling regarding patient's condition, addressing fears, as well as being supplied with general information regarding patient care which should also be in writing would help the caregivers to cope better. Guidelines by Hudson (2009) describe that family caregivers require ongoing information regarding patient's condition to enhance coping. Food handouts and free home visits by Island Hospice would go a long way in alleviate issues of food security and problems with cash.

Family caregivers need counselling during the time they will be caring for a patient. This is because the experience engenders emotional and spiritual pain on a daily basis during the patient's illness. The issue of financial assistance and food handouts was strongly emphasised. The use of the extended family to provide for the patient's practical needs was not working as the extended family members were also reeling in poverty and most of them were rural based and unable to visit regularly. This also affected provision of emotional care as the caregivers had no relatives readily available.

The respondents explained the importance of being given relevant information at and during all stages of the disease. They felt that the information would empower them such information to include the how to provide hands on care, symptom management using home remedies, the dying process, and preparation for death. They expressed the need for regular home visits towards the end of the patient's life. The caregivers explained the need for respite as providing care to the patient on a daily basis was exhausting them. It was feasible for those caregivers with willing relatives but it proved to be a problem for those whose relatives live far from the patient

Some respondents reported that they would forget information regarding patient care, which would have been given to them by the Island Hospice team. They preferred having pamphlets and other information and educational materials which they would remain reading and sharing with other family members.

5.10 Spiritual and Cultural Considerations

Traditional and faith healers provide treatment and care to willing patients who will be taken there by family members. The traditional healers are protected by the government of Zimbabwe where they have to be registered under the Traditional Healers Association. Traditional healers mirror the conventional health delivery system. Witchcraft accusations are mainly fuelled by deteriorating patients' conditions. This creates conflict in the family particularly with other family members who do not like to be treated by traditional healers. The health care providers are aware that patients can choose whom they want to consult during the course of illness and that they can consult both traditional healers and medical doctors at the same time.

Any chronic illness that a patient has is viewed by some Shona and Ndebele to have been caused by enemies who bewitched the patient. The intervention for a bewitched person is done by consulting a traditional healer or a faith healer. The traditional healer will first diagnose the cause of illness then provide treatment. The traditional healers use various methods to treat the bewitched person, which include giving concoctions, which induce vomiting, or piercing the patient's skin and applying medical powder, or instruct family members to perform certain rituals for the patient to be healed. This intervention results in time being wasted to consult conventional medical interventions and patients present late as a result while other patients default treatment.

This concurs with the findings of Drew *et al* (2000) who highlighted that in Shona language practice, a sick patient is taken to a traditional healer who will diagnose cause of illness and give medication to overcome the spirit causing the illness. All diseases are perceived as curable and the concept of terminal illness is alien.

The church also plays an important role in supporting the patient spiritually, financially and emotionally. When church members visit they may bring food and cash, this kind of support is needed in times of illness and if this support is withdrawn it leads to extended poverty and anxiety to the caregiver. In this study, the spiritual pain was apparent especially when participants expressed the poverty that they were experiencing. In this research, dysfunctional families are failing to develop new styles of coping when faced with the tasks that are tied to the current illness in the family. Some bemoaned lack of practical skills in providing care as well as stigma and discrimination by the church and the community.

5.11 Benefits of Emergency Unit

With the current situation in the country where there are numerous constraints due to the economic meltdown, it appears that the emergency unit would be a better option for family caregivers to send their patients to for management. The family members are to be educated to inform the nurse on call when they take patients to the emergency unit. Family members expressed the fact that they expected the patient to get better care in the emergency unit, admission to hospital that would ensure access to food and medicines. Hospital admission would ensure 24hr a day care which family caregivers felt inadequate about providing the level of care required. In addition, even if the patient died in hospital the extended family would know that the caregiver had accessed hospital care for the patient.

5.12 Death at Home

The responses from the participants surveyed have revealed that death at home is not accepted. The perception of the severity of the illness by the family prompted them take the patients to the hospital as the families would be afraid that the patient might die at home. In some instances the patients themselves were the ones who requested to be taken to the emergency unit as they feared dying at home. The family caregivers need constant home visits by the palliative care team as a way of supervising and supporting the caring work they are doing. The family caregivers would like twenty-four hour coverage daily by Island Hospice as they felt it would help to alleviate their anxieties knowing that they can call on Island Hospice at anytime.

Some respondents expressed that by taking the patient to the emergency unit they had hoped that the patients would be admitted in hospital where they hoped that he would receive better

care. The fact that they had never cared for a patient with such distressing symptoms made them decide to take them to the emergency unit. This is related to the caregivers' confidence in providing care during the period when the patient was ill.

5.13 Limitations of the Study

Because the study design was purposive sampling, some participants had reservations to participate which may have affected the results of the findings. The investigator was not able to get equitable representation because the poorest people approached refused to participate as they weren't going to be paid for participating.

The research was carried out in a poor resource setting, thus the results may not be used to intervene on caregivers from other settings, and however the findings can be used as a baseline for interventions in programming.

CHAPTER 6: CONCLUSION AND IMPLICATIONS FOR FINDINGS

6.1 Conclusion

The objectives of the study were met through the analysis of the data that was collected from the interviews conducted with 15 family caregivers caring for patients under Island Hospice. The themes generated from the study have given answers to the events that influence families to take terminally ill patients to the emergency unit. The data collected helped to identify challenges experienced by family caregivers in providing end of life care at home and identify what form of support families would like to have towards the patient's end of life. The respondents interviewed do not support the idea of home deaths, they would rather send patients to the emergency rooms.

The responses collected by the researcher indicated that family caregivers have unmet needs in their daily duties of caring for patients. Generally family caregivers do not have adequate emotional support from the palliative care team members due to various reasons to this issue. The issue of finances was sighted as the main reason for caregivers not reporting the patient's condition to the palliative care team since families are expected to pay for the home visits. In addition, the issue of unavailability of the team after working hours and during the night made it difficult for families to call the palliative care team during their times of need. These unmet needs result in the caregivers' inability to cope with providing care to the patients. It emerged that as a result of witnessing the patient suffering from pain, and other distressing symptoms the family caregivers feel helpless and are afraid that they may be contributing to the patients suffering.

The findings also showed that patients also had unaddressed psychosocial needs these combined with the poor socio-economic situation prevailing in the country resulted in the

caregivers inability to cope with the patients at home. The study also showed that the caregivers suffer from compassionate burn out whereby they end up hoping that the patients would end up being admitted in hospitals thereby providing them with respite. It emerged that some family caregivers could not cope with looking after the patients at home on their own, as they felt isolated; this was compounded by the caregivers' fears of death. The findings showed that in other instances the patients are the ones who request to be taken to the emergency unit. Cultural issues including witchcraft accusations, were another reason where patients were taken to the emergency unit under the belief that everything must be done for a patient to prevent them from dying. However the respondents highlighted that they meant well and were concerned about the physical wellbeing of the patients.

6.2 Implications of the findings

In light of this research study the following suggestions are made to Island Hospice:

6.2.1 That Island Hospice should develop protocols and procedures for families to follow when they are feeling that they are unable to take care of the patient at home. The current situation is that family caregivers can do what they think is right for them and sometimes they do not inform Island Hospice, or they inform Island Hospice when the patient has been admitted already.

6.2.2 All the caregivers interviewed appreciated the medication they are receiving from Island Hospice but however, questioned the effectiveness of the medication without food. Thus they hoped it will be possible for Island Hospice to provide food handouts and increase the amount of medications they supplied to the patients.

6.2.3 That Island Hospice should effectively address the issue of families that are not able to pay for the service because some families hesitate to approach Island Hospice due to lack of cash thereby depriving patients access to palliative care. Chronic illnesses have a negative bearing on financial stability, therefore there is need to provide counselling for the direct and indirect financial burdens associated with chronic illness. With regards the poor economic situation of the country, efforts should be made to raise funds in order to support those who cannot pay for the services.

6.2.4 Island Hospice Service to revisit the on call system by increasing hours of the on call service to cover all the hours of the day so that there is total coverage. This will reassure patients and family members who feel isolated and they panic resulting in them seeking help from the emergency rooms.

6.2.5 Island Hospice should partner with a hospital which enable them to provide in-patient palliative care. This will go a long way to ensure the issue of respite for both the patient and the caregiver. The caregiver will have an opportunity to nurture self while the patient is admitted.

6.2.6 Island Hospice to develop support group programmes for family caregivers where they meet with other in the same situations as them and share experiences and learn from each other. This will go a long way in reducing stress levels among the family caregivers.

6.2.7 Island Hospice to develop information and educational materials as handouts, the handouts should also be in vernacular and should provide information regarding provision of practical care capacity building for family caregivers should be in place to ensure that family caregivers have the relevant knowledge and skills to care and improve their ability to care

whilst at the same time improving their quality of life. The caregivers should be equipped with home based care kits and ensured of follow up and support from the community home based caregivers. Furthermore, there is need to continuously educate caregivers on changing trends on caring for patients. This has a positive effect on diminishing caregivers' sense of helplessness by empowering them with knowledge and skills to enhance patient comfort through the use of drugs.

6.2.8 Island Hospice to adopt the CSNAT tool to identify what form of support families would like to have towards the patient's end of life

6.2.9 Island Hospice to advocate for the needs of family caregivers using different means of communication such as media, The community in general needs to be educated on the plight of family caregivers who are looking after the sick at home so that there will be better informed to support the family caregivers.

6.2.10 Island Hospice should engage the department of social services as well as the corporate sector in order to support the family caregivers in need. They should source food packs to be handed to needy patients. Thorough needs assessments to be conducted before handing food packs to avoid creating a dependency syndrome.

6.2.11 Island Hospice to develop a culture of involving patients and family caregivers in developing end of life care planning for patients which should include discussion of anticipated symptoms and management of same. The caregivers would benefit from constant reassurance and affirmation of the good work they are doing. Care planning for patients to include discussion of anticipated symptoms and the caregivers would benefit from constant reassurance and affirmation of the good work they are doing. Preparing of patients and family

caregivers for death and providing on -going counselling and support will enhance family coping. This support is achievable through the expertise of using the interdisciplinary team approach.

6.2.12 It is recommended that Island Hospice should develop a culture of assessing family communication patterns prior to and during the course of the illness. Good communication skills have a positive impact on patient care. Family conferences should be conducted when the need arises. There is need to establish mechanisms for conducting family conferences to facilitate shared communication between patient, family and health providers. This enables a patient to receive quality care and communicate changing goals of care there is need to assess whether multiple family crises exist, for instance, recent retirement, births or divorce. These developments have an influence in the way family cope with illness. Furthermore, there is need to recognise areas of concurrent stress which may be unrelated to the patient or illness, for instance, job loss, stress of extended family and coping with children. It is of fundamental importance to provide information about different trajectories of death to the community caregivers which will enable them to support families.

Recommendation to Policymakers

6.13 All health professionals should be trained in palliative care as this will go a long way to ensure quality of care for patients and families where ever they are.

6.14 The national palliative care association (HOSPAZ) and The Ministry of Health and Child Care need to ensure that the needs of family caregivers are represented within the needs of key populations in the National Palliative Care Strategy emanating from the recently introduced National Palliative Care Policy

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Appendix 1 Semi Structured Interview Guide

RESEARCH QUESTION

What are the issues that influence family caregivers of patients receiving palliative care from island hospice to seek help at emergency unit?

SEMI STRUCTURED INTERVIEW GUIDE

After introduction and building rapport the researcher will begin with the following statement as a way of collecting the respondent's demographic data;

DEMOGRAPHIC DATA

First I would like to ask you about your age, level of education, marital status and how you are related with the patient.

Age

Level of education

Marital status

Relationship to ….

Then the researcher will move to communicate about the patient as below:

1. Tell me the story of your .....illness. The investigator will use prompts as necessary including:

- Worry/anxiety with regard to patient's illness
- Patient's condition
- What are their expectations of care? Provided by hospice? Provided by emergency unit? Outcomes
- Will ask about dying only if they bring it up

2 What are the challenges that you are facing in caring for your ……at home?

3 Has your .....ever gone to the emergency unit?

- Why did s/he go to EU
- How did you decide to go to EU?
- What happened there?

4 What are your family's expectations regarding your……'s condition

5 How are you providing care to your ..... at home?

6 Is there anything else that you would like to mention regarding your …….illness? YES/ NO . If yes please explain

Appendix 2 Information sheet prior to consent and consent to be signed

Information Sheet for:

Family Care Giver Respondents who would like to participate in A Case Study for Island Hospice

Thank you for giving your time to hear about our study.

This information sheet tells you about this study that you may wish to take part in. You may have some further questions to help you decide whether you want to take part. You can ask any further questions from your clinical team, from the researcher, or using the telephone numbers at the end.

Thank you for thinking about whether you want to take part. Please take your time to make a decision.

What is the purpose of the study?

The study is looking at challenges being experienced by family caregivers in providing end of life care at home. It also seeks to explore factors influencing family care givers caring for patients under Island Hospice to send patients to the emergency unit at any time during the patient's illness.

Do I have to take part?

No, you don't have to take part. If you do agree to take part, you are free to withdraw from the interview at any time without giving us any reason. Whether or not you take part, the care your family is receiving will NOT be affected in ANY WAY. If you do agree to take part, you will be asked to sign a consent form, which shows that you have agreed to do so. You can take some time to think about whether you would like to take part, and you may want to talk it over with your family, friends or someone in your care team.

If you do agree to participate in the study, you will be required to sign a consent form which you will be given on the day of the interview.

What will happen if I take part?

An experienced researcher will interview you using an audiotape and ask you questions about your relative's health and illness, caring for the patient at home, health care choices. The interview will take around 30 to 45 minutes of your time.

Benefits of the study

There are no direct benefits to the study for participants though the anticipated benefits are in identifying family care giver's needs and in trying develop interventions to meet those needs.

What are the risks of the study?

There are few study risks. Answering some questions might cause you to feel emotionally distressed. The researchers and counsellors are trained to assist if you are upset or distressed. The researcher will stop the study and ask you if you would like assistance such as counselling support.

Will my taking part in this study be kept confidential?

All the information which we collect during the interview will be kept strictly confidential. You will not be identified in any way, and your personal details (for example name and address) will be kept separately from the information you give. We will use a number and not your name on any information you give us. No-one outside the study will have access to the information you give us.

How will I know about the results of the study?

At the end of the study a report will be sent to Island Hospice and to the people who took part in the study.

Who is organizing the research?

If you need to talk to anyone about this research, you can contact the following people.

If you have any questions about the study:

Sr Franciscah Tsikai a student with the University of Cape Town: Tel + 263 773056640

Under the supervision of Dr Liz Gwyther Tel +27 21-4066707

If you have any questions regarding human rights and ethical issues related to the study you can contact ;

(1)

The community Teams Manager,

Island Hospice Service.

6 Natal Road

Belgravia

Harare

Zimbabwe

Telephone +263 4.701674 -7

(2)

The Human Research Ethics Committee

University of Cape Town

Faculty of Health Sciences

E52, Room 24. Old Main Building,

Groote Schuur Hospital,

Observatory. Cape Town.

Telephone +27 21 406 6492

(3)

The Medical Research Council of Zimbabwe,

P.O. Box CY 573.

Causeway.

Harare . Zimbabwe

CONSENT FORM TO BE SIGNED

Statement of Consent

1. I confirm that I have read and understood the information sheet and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and I am free to withdraw at any time, without giving a reason, without my care being affected.

3. I agree to take part in the above study as a primary care giver.

4. I agree for the interview to be audio taped and transcribed

Name _____

Signature _____ Date _____

Researcher: Signature _____ Date: _____

Witness: Name

(from clinical team or family member)

Signature _____ Date: _____

Appendix 3 Approval letter from HEREC

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

Room E52-24 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6338 • **Facsimile** [021] 406 6411
Email: shuretta.thomas@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

30 October 2015

HREC REF: 777/2015

Dr L Gwyther
Family Medicine
2.28 Falmouth Building

Dear Dr Gwyther

PROJECT TITLE: A STUDY TO EXPLORE ISSUES THAT INFLUENCE FAMILY CAREGIVERS OF PATIENTS RECEIVING PALLIATIVE CARE FROM ISLAND HOSPICE TO SEEK HELP AT EMERGENCY UNIT (MPhil-candidate-F Tsikai)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee.

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

- Approval from local site
- Please add what will happen to audiotapes at the study end; to the informed consent document.

Approval is granted for one year until the 30th October 2016.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please quote the HREC REF in all your correspondence.

We acknowledge that the student, Franciscah Tsikai will also be involved in this study.

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

Yours sincerely

Signed

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI),and Declaration of Helsinki (2013) guidelines.
The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

HREC 777/2015

Appendix 4 Approval letter from MRCZ

Telephone: 791792/791193
Telefax: (263) - 4 - 790715
E-mail: mrcz@mrcz.org.zw
Website: http://www.mrcz.org.zw

Medical Research Council of Zimbabwe
Josiah Tongogara / Mazoe Street
P. O. Box CY 573
Causeway
Harare

MRCZ APPROVAL LETTER

Ref: **MRCZ/B/956** **18 January, 2016**

Franciscah Tsikai
Island Hospice & Healthcare
6 Natal Road
Belgravia
Harare
Zimbabwe

RE: A STUDY TO DETERMINE ISSUES THAT INFLUENCE FAMILY CAREGIVIERS OF PATIENT RECEIVING PALLIATIVE CARE FROM ISLAND HOSPICE TO SEEK HELP AT EMERGENCY UNIT

Thank you for the above titled proposal that you submitted to the Medical Research Council of Zimbabwe (MRCZ) for review. Please be advised that the Medical Research Council of Zimbabwe has **reviewed** and **approved** your application to conduct the above titled study. This is based on the following documents that were submitted to the MRCZ for review:

a) Study proposal.
b) English and Shona Consent Forms

- **APPROVAL NUMBER** : **MRCZ/B/956**

This number should be used on all correspondence, consent forms and documents as appropriate.

- **APPROVAL DATE** : **18 January, 2016**
- **EXPIRATION DATE** : **17 January, 2017**
- **TYPE OF MEETING** : **EXPEDITED REVIEW**

After expiry date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the MRCZ Offices should be submitted one month before the expiration date for continuing review.

- **SERIOUS ADVERSE EVENT REPORTING**: All serious problems having to do with subject safety must be reported to the Institutional Ethical Review Committee (IERC) as well as the MRCZ within 3 working days using standard forms obtainable from the MRCZ Offices.
- **MODIFICATIONS**: Prior MRCZ and IERC approval using standard forms obtainable from the MRCZ Offices is required before implementing any changes in the Protocol (including changes in the consent documents).
- **TERMINATION OF STUDY**: On termination of a study, a report has to be submitted to the MRCZ using standard forms obtainable from the MRCZ Offices.
- **QUESTIONS**: Please contact the MRCZ on Telephone No. (04) 791792, 791193 or by e-mail on mrcz@mrcz.org.zw.co.zw.
- **Other**
- Please be reminded to send in copies of your research results for our records as well as for Health Research Database.
- You're also encouraged to submit electronic copies of your publications in peer-reviewed journals that may emanate from this study.

Yours Faithfully

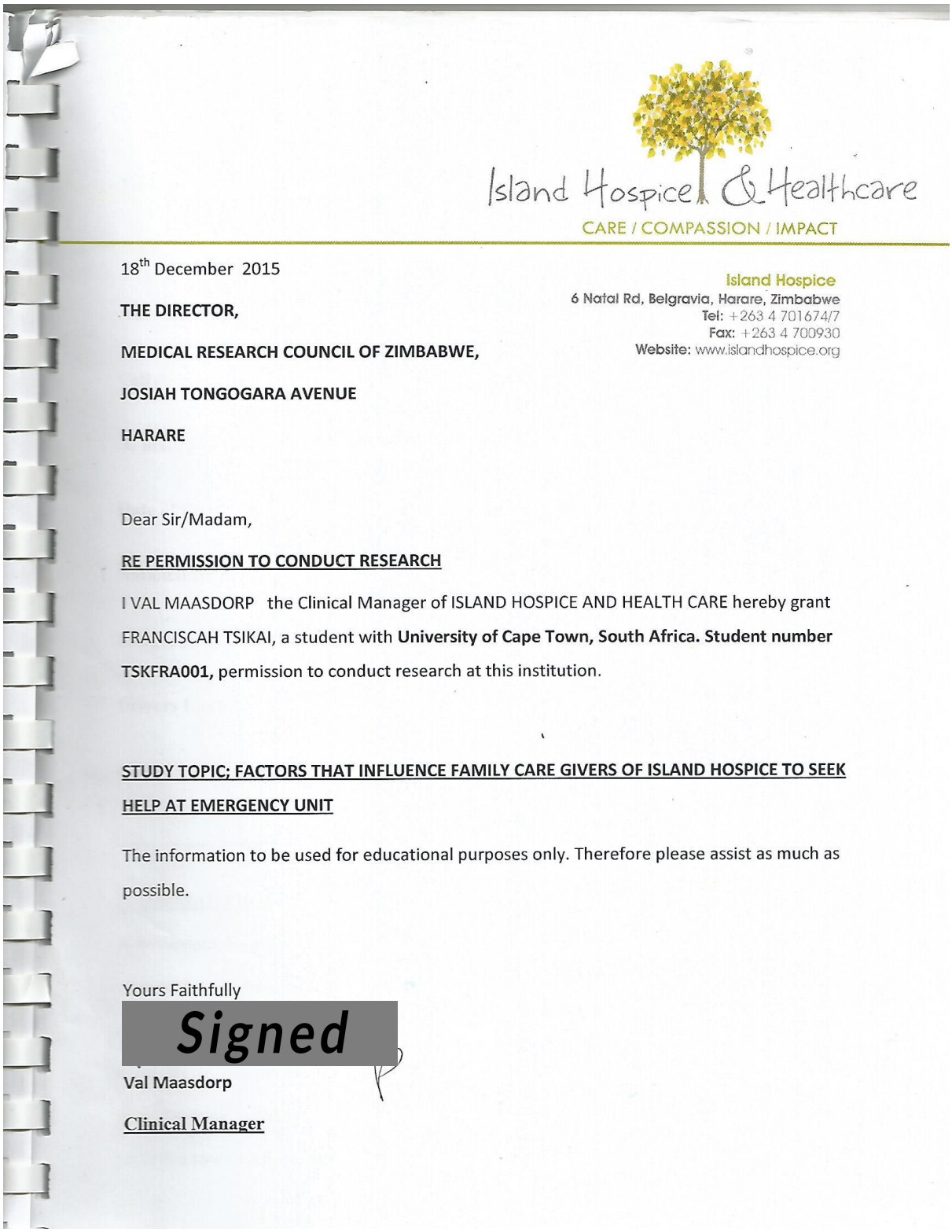
Signed .....

MEDICAL RESEARCH COUNCIL OF ZIMBABWE
18 JAN 2016
APPROVED
P. O. BOX CY 573 CAUSEWAY, HARARE

MRCZ SECRETARIAT
FOR CHAIRPERSON
MEDICAL RESEARCH COUNCIL OF ZIMBABWE

PROMOTING THE ETHICAL CONDUCT OF HEALTH RESEARCH

Appendix 5 permission letter from Island Hospice



Island Hospice & Healthcare
CARE / COMPASSION / IMPACT

18th December 2015

Island Hospice
6 Natal Rd, Belgravia, Harare, Zimbabwe
Tel: +263 4 701674/7
Fax: +263 4 700930
Website: www.islandhospice.org

THE DIRECTOR,

MEDICAL RESEARCH COUNCIL OF ZIMBABWE,

JOSIAH TONGOGARA AVENUE

HARARE

Dear Sir/Madam,

RE PERMISSION TO CONDUCT RESEARCH

I VAL MAASDORP the Clinical Manager of ISLAND HOSPICE AND HEALTH CARE hereby grant FRANCISCAH TSIKAI, a student with **University of Cape Town, South Africa. Student number TSKFRA001,** permission to conduct research at this institution.

STUDY TOPIC; FACTORS THAT INFLUENCE FAMILY CARE GIVERS OF ISLAND HOSPICE TO SEEK HELP AT EMERGENCY UNIT

The information to be used for educational purposes only. Therefore please assist as much as possible.

Yours Faithfully

Signed

Val Maasdorp

Clinical Manager