AN EXPLORATION OF PATIENTS' PREFERENCES AND PRIORITIES FOR END-OF-LIFE CARE AT TIYANJANE CLINIC FOR PALLIATIVE CARE, QUEEN ELIZABETH CENTRAL HOSPITAL, BLANTYRE, MALAWI

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DISSERTATION

IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE MPHIL IN PALLIATIVE MEDICINE

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DECLARATION

I, ALEX JACKSON CHITANI, hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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Date: 16th December 2017

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Abbreviations

AIDS: Acquired Immune Deficiency Syndrome

ART: Anti-Retroviral Therapy

COM: College of Medicine

COMREC: College of Medicine Research Ethics Committee

HIV: Human Immune Virus

KS: Kaposi Sarcoma

NCDs: Non-communicable diseases

PCST: Palliative Care Support Trust

QECH: Queen Elizabeth Central Hospital

UCT: University of Cape Town

UCT HREC: University of Cape Town Human Research Ethics Committee

UK: United Kingdom

UNIMA: University of Malawi United

UNAIDS: United Nations Programme on HIV and AIDS

WHO: World Health Organization

Abstract

Background

For patients to have a dignified death, their wishes should be known and respected. The challenge is that, if conversations about death are avoided by patients, their families and health professionals because talking about death is taboo, it becomes hard to plan and implement preferred care for such patients. The researcher undertook an exploration of patients' preferences and priorities for end-of-life care at Tiyanjane Clinic for palliative care, Queen Elizabeth Central Hospital, Blantyre, Malawi. The topic is regarded as sensitive and taboo in Malawi because discussing end-of-life care preferences and priorities is taken as prophesying death.

Methodology

This was a qualitative, descriptive study. Equal opportunity to participate in the study was provided to all adult patients diagnosed with life-threatening illnesses at the Clinic. Most participants were infected with the HIV virus. Data was collected by means of semi-structured interviews that were recorded and afterwards transcribed verbatim. A thematic framework was used to inform the systematic approach to data analysis.

Results

In December 2015 and January 2016, interviews were conducted with 14 adults (six men and eight women). The following 10 themes emerged from the data: Awareness of reason for being at Tiyanjane; reluctance to mention HIV; psychosocial concerns, expressed emotions; legacy; receiving information; decision-making; place of care; place of death; and spiritual concerns.

Conclusion

This research shows that, although choices are limited in Malawi due to a lack of resources, patients need to be given an opportunity to make their own healthcare choices. This research has shown that it is not as hard to start end-of-life care conversations as previously thought. Further research needs to explore whether advance directives or legal wills should be offered as part of care for palliative patients in Malawi, as most of the participants highlighted the need to be heard in regard to their wishes being upheld after death.

1.0 Chapter One: Introduction

This study investigated patients' preferences and priorities for end-of-life care. The study intended to explore patients' current knowledge, thoughts about and gaps in information in regard to their illness; assess how much information patients would like to be given about their illness; assess patients' choices in being involved in their healthcare decisions; determine patients' willingness to discuss and level of comfort in discussing end-of-life issues; and investigate whether patients had a preferred place of death.

A good understanding by patients and their families of their disease could assist patients and their families in thinking about realistic goals for any care option, assist in planning for future care preferences and guide the documenting of patients' wishes.

There is little or no literature about end-of-life care in Malawi. The topic is regarded as sensitive and taboo, because discussing end-of-life care preferences and priorities is taken as prophesying death in a Malawian setting. However, the *Malawi National STEPS Survey for Chronic Non-Communicable Diseases Report,* published in 2010, and the *Malawi AIDS Response Progress Report*, published in 2015, mentions that the burden of HIV, cancer and other non-communicable diseases is high in Malawi [1, 2]. Although it is hard to initiate end-of-life conversations, discussing preferences and priorities at the end of patients' lives could help patients and their families make appropriate and realistic plans for the remaining time of their lives.

For patients to have a dignified death, their wishes should be known and respected. Kikule in Kampala, Uganda, stated in 2000 that a good death occurs at home, in the absence of pain and other distressing symptoms, without stigma or a sense of dependence, and with adequate finances for the basics [3]. The challenge is that, if conversations about death are avoided by patients, their families and health professionals because it is taboo, it becomes hard to plan and implement preferred care for such patients.

Back et al in 2010 mentioned that, for patients, a terminal diagnosis signals entry into what one writer had called "the country of illness"- a complex world involving loss, decisions, therapies, waiting and work [4]. From the time of a terminal diagnosis, patients start a journey with many

challenges that require much planning [4]. Bates et al in 2011 stated that it is the duty of healthcare professionals to check patients' understanding of their terminal diagnosis; ask patients whether they would like to know more about their illness, the prognosis, available care options, benefits and burdens of each care option; and then involve the patients and their families in planning for the future [5]. It was deemed important for this study to establish the willingness of patients with terminal diagnoses in Malawi to engage in end-of-life care conversations. In addition, it was also deemed important to find out whether patients were able to express their wishes in regard to their preferred place of care and their preferred place of death.

From the researcher's observation at QECH, one of the challenges that patients with terminal diagnoses face is to make difficult decisions about the remaining part of their lives. That is the time when realistic goals of care need to be developed according to patients' preferences and priorities. For example, where do patients want to be cared for, what treatment options are available and what are the benefits and burdens of each treatment option in a Malawian setting? What about communication challenges in terms of diagnosis disclosure to patients and their families by healthcare workers? What are the patients' main concerns about end-of- life care in Malawi? Where would patients prefer to die and why? The challenges may relate specifically to physical, psychosocial or spiritual challenges or could be a combination of any or all of these.

There is no data available about end-of-life care challenges in Malawi that may guide the design and provision of end-of-life care interventions. Currently, end-of-life care interventions in Malawi are based on the experiences of healthcare workers and not on evidence-based practice. At QECH, it is healthcare workers who are tasked with the responsibility of breaking bad news and discussing future care options after a patient has received his or her test result. Breaking bad news is at the forefront of a series of essential, challenging conversations that need to take place along the journey of a patient's illness.

1.1 Burden of cancer, other non-communicable diseases and HIV

Globally

According to Cancer Research UK in 2015, there were 14.1 million new cases of cancer world-wide in 2012 and 8.2 million deaths from cancer world-wide in 2012 [6]. Additionally, Stjernsward et al stated that seven million of the 10 million new cases of cancer diagnosed each year were not cured and that such patients died within a year of diagnosis. It was further reported that the prevalence of cancer would double to an estimated incidence of 24 million new cases per year by 2050 [7].

The World Health Organization (WHO) in 2010 reported that, out of 57 million deaths that occurred globally in 2008, 36 million deaths were due to non-communicable diseases. These included mainly cardiovascular diseases, cancers, diabetes and chronic lung diseases [8]. The WHO further stated that the burden of these diseases was worsening in lower income countries, where they imposed large, avoidable costs in human, social and economic terms [8]. Finally, the WHO reported that over 80% of cardiovascular and diabetes deaths and approximately 90% of deaths from chronic obstructive pulmonary disease occurred in low- and middle-income countries [8].

In 2016, 1st December Word AIDS Day, UNAIDS reported that a total of approximately 36.7 million (34.0 million to 39.8 million) people had been living with HIV globally by the end of 2015 [9]. Approximately 35 million (29.6 million to 40.8 million) people had died by the end of 2015 from AIDS-related conditions since the start of the epidemic [9]. Tuberculosis remained the major cause of death among people living with HIV globally, with a proportion of around one in three AIDS-related deaths [9].

Africa

According to American Cancer Society, most cancers in Africa are diagnosed at an advanced stage because of a lack of resources [10]. In 2011 American Cancer Society stated that approximately 715,000 new cancer cases and 542,000 deaths had been registered in Africa at that time[10]. It was projected that cancer figures would double to 1.28 million new cancer cases and 970,000 cancer deaths by the year 2030 [10]. However, despite the increasing burden of cancer in Africa, cancer

continued to have low public health priority in Africa because of a lack of resources and other pressing public health diseases such as communicable diseases like Acquired Immunodeficiency Syndrome (AIDS), malaria and tuberculosis [10]. Non-communicable diseases (NCDs) like diabetes, stroke and chronic kidney disease were also becoming a burden in Africa [10].

UNAIDS in 2016 reported that approximately 19 million (17.7 million to 20.5 million) people had been living with HIV in Eastern and Southern Africa alone in 2015 [9]. Approximately 470, 000 (390,000 to 560, 000) people had died of HIV-related causes in Eastern and Southern Africa alone in 2015 [9].

Malawi

Msyamboza et al conducted a nationwide cancer registry between September and October 2010 in Malawi [11]. They reported that the most prevalent cancers in males in Malawi between 2007 and 2010 were Kaposi sarcoma (50.7%); oesophageal cancer (16.9 %); Non-Hodgkin Lymphoma (7.8%); prostate cancer (4.0%); bladder cancer (3.7%); cancer of the eye (2.7%); cancers of the stomach, intestine, and anus (1.8%); bone cancer (1.6%); liver cancer (1.5%); cancer of the penis (1.4%); kidney cancer (0.4%); breast cancer (0.3%); lung cancer (0.2%); and other cancers (7.1%)[11].

The most common cancers in females in Malawi between 2007 to 2010 were cervical cancer (45.4%); Kaposi sarcoma (21.1%); oesophageal cancer (8.2%); breast cancer (4.6%); Non-Hodgkin Lymphoma (4.1%); cancer of the eye (2.5%); bladder cancer (2.2%); cancers of the stomach, intestine and anus (1.4%); bone cancer (1.2%); ovarian cancer (0.9%); liver cancer (0.7%); kidney cancer (0.4%); lung cancer (0.1%); and other cancers (7.2%)[11].

The Ministry of Health and the College of Medicine in Malawi, in collaboration with the World Health Organization, conducted a survey in 2009 of the prevalence of non-communicable diseases in Malawi [1]. The aim of the survey was to determine the prevalence of hypertension, diabetes and raised cholesterol levels and their risk factors. A total of 5,206 participants were recruited for the study. The results showed that a third (32.9%) of the participants had raised blood pressure, 5.6% had diabetes and 8.7% had raised cholesterol levels [1]. Unfortunately, the

majority (94.9%) of the people with high blood pressure were not on medication and/or were not aware that they were hypertensive [1].

The *Malawi AIDS Response Progress Report* in 2015 stated that no recent representative national survey had been conducted in Malawi since 2010 [2]. However, based on previous data, HIV prevalence among people aged 15 to 49 years had ranged from 16% in 1999 to 11.8% in 2004 and 10.6% in 2010 [2]. Despite this large burden of HIV/AIDS and cancer, the impact of having limited resources on patients receiving end-of-life care is not known in Malawi. An example of such limited resources is that, at QECH, some oxygen-dependent palliative care patients cannot access oxygen at home because few oxygen concentrators are available within the hospital setting and even fewer in the context of home care.

1.2 Definition of palliative care

The WHO in 2002 defined palliative care as 'an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illnesses, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.'[12]

Palliative care provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten nor postpone death; integrates the psychological and spiritual aspects of patient care; offers support systems to help patients and their families live as actively as possible until death; offers a support system to help the family cope during the patient's illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated; will enhance quality of life and may also positively influence the course of the illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiotherapy; and includes those investigations needed to better understand and manage distressing clinical complications [12].

1.3 When to start palliative care

Murray and Mason in 2016 stated that palliative care starts at the time of diagnosis [13]. At the time of diagnosis there are many disease-modifying agents like anti-retroviral therapy (ART) and chemotherapy but, as the disease progresses, palliative care becomes more prominent. Once the diagnosis has been made, there is more focus on curative treatment, but, as time progresses, curative options become fewer, while palliative care plays an increasingly important part. It is important to start the conversation about end-of-life care preferences and priorities at the time of diagnosis, so that patients have enough time to make their advanced care plans. At the end of life, the goal of care tends to shift from ongoing curative measures to palliative care for control of pain, symptoms and emotional stress.

The old concept of palliative care was that palliative care should be commenced when a patient was approaching death. The improved concept states that palliative care should start at the time of diagnosis. (See Figure 1. below)

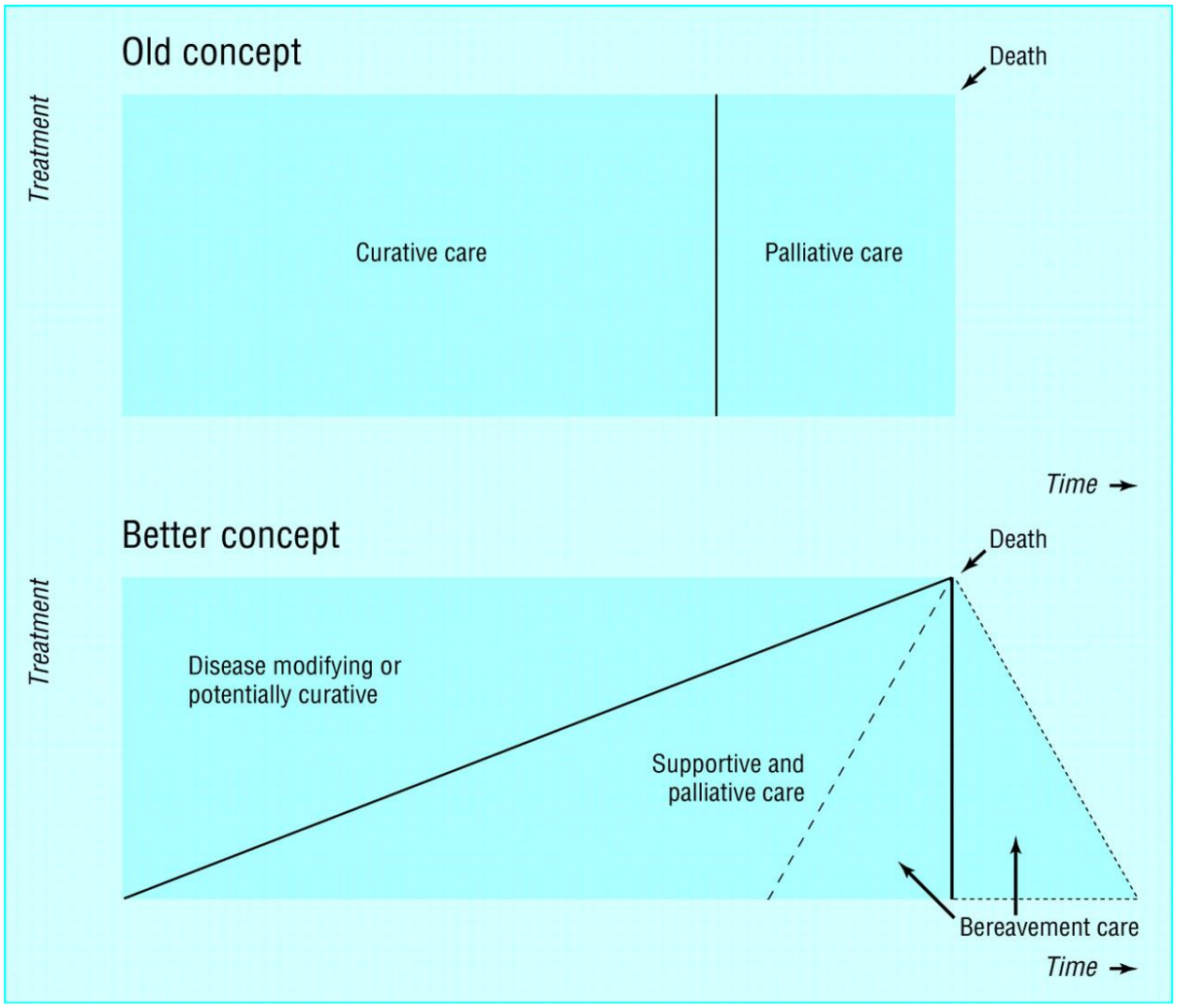

Figure 1. When to start palliative care [13]?

1.4 Communication skills when breaking bad news

Buckman mentioned that truth-telling requires 'greater thought and planning than a drug prescription' [14]. The aims of breaking bad news are to gather information from the patient, to provide information to the patient, to support the patient in his or her emotional response and to involve the patient in planning for the treatment [14]. There is universal discomfort about or awkwardness in having conversations about end-of-life care with terminally ill patients [14]. In addition, Buckman stated that adequate information disclosure leads to effective symptom control [14].

Back et al in 2010 stated that the task of breaking bad news had been renamed 'talking about serious news', because the task of breaking bad news was viewed as information dumping and talking about serious news framed the task more constructively for the healthcare worker and the patient [4]. At QECH, healthcare workers identified with such a claim and associated their discomfort with their own lack of effective communication skills, which contributed to the fact that many patients were not informed about the seriousness of their diagnosis.

Baile et al suggested that healthcare workers might be guided by the SPIKES protocol for breaking bad news in their respective work settings [15].

S	SETTING up the interview and listening skills
P	Patient's PERCEPTION of the condition and its seriousness
I	INVITATION to patient to receive information
K	Giving KNOWLEDGE to patient (i.e. giving medical facts)
E	Addressing the patient's EMOTIONS and empathizing as patient responds
S	STRATEGY and SUMMARY

Figure 2: The SPIKES protocol [15].

Bates et al in 2011 further simplified the SPIKES protocol to ASK-ASK-TELL and ASK-ASK-PLAN to suit the Malawian setting [5].

In this researcher's view, the ASK-ASK-TELL ASK-ASK-PLAN model for breaking bad news could be a useful guideline for breaking bad news in Malawi.

- Ask yourself: The one breaking the bad news should ask himself or herself about the availability of the right information about the diagnosis, the appropriate time and a convenient place for breaking the bad news without interruption.
- Ask about the patient's understanding of the illness or what has he or she been told about the illness by other doctors or nurses who are looking after the patient.
- Tell the patient and the guardian, in simple language, slowly, clearly and in small chunks, about the illness and check the response.

- Ask the patient what he or she understands about the word “cancer” or the illness.
- Ask the patient about his or her main concerns and invite any other questions concerning the illness.
- Plan the future with the patient in terms of treatment, referrals and follow-ups.

1.5 Palliative care education, research and training

Palliative care is a new concept in Malawi and there is a need for knowledge, skills and training of professionals across all disciplines, including specialist practitioners, all other healthcare workers, social workers, community leaders and spiritual leaders. Scot et al in 1998 stated that palliative care education should be seen as a basic component of undergraduate and postgraduate curricula [16]. Powel et al in 2008 argued that, for progress to be made in the provision of palliative care, research has to complement the provision of palliative care [17]. End-of-life care preferences and priorities are one such area that needs to be explored.

The challenge in Malawi is that many healthcare workers graduate from colleges without learning about palliative care. In Malawi, many nursing colleges and the Malawi College of Health Sciences do not include palliative care concepts - of which communication skills are an essential component - in their curricula, except for the Malawi College of Medicine. Palliative care education and training intend to equip healthcare workers with effective communication skills so that they will be able to explain to patients the available treatment options in Malawi.

Alelwani and Ahmed did a literature review of medical training for the communication of bad news [18]. The review aimed to evaluate the existing evidence of the benefits of training in breaking bad news. PubMed, LILACS, and SciELO databases were reviewed. Seven studies were identified in the search and, of the seven studies, only four studies showed an improvement in trainees after their training [18]. However, it was found that communication training was conducted in different ways, with content and duration of communication training differing in each study [18]. The conclusion was that the training of undergraduate and postgraduate physicians in skills for disclosing bad news might be beneficial. The limitation of this literature review is that few studies were designed appropriately to evaluate the training programmes.

2.0 Chapter two: Literature Review

A literature review was conducted to collect information about patients' preferences and priorities for end-of-life care.

The literature search was done electronically, using PubMed and Medline. The search phrases used included "cancer burden", "end-of-life experience", "information disclosure", "decision-making", "palliative care education", and "place of death". The Oxford Textbook of Palliative Medicine was also used to search the literature manually.

The literature review articles have been arranged in the following categories: End-of-life care experience, decision-making, place of care and place of death.

2.1 The burden of end-of-life care

Gysels et al conducted a systematic review of the qualitative literature about end-of-life care in sub-Saharan Africa [19]. The systemic review aimed to analyse qualitative research about end-of-life care with the aim of influencing policy, practice and future research in sub-Saharan Africa. Appropriate literature was searched through eight electronic databases: AMED, the British Nursing Index and Achieve, CINHL, EMBASE, IBSS, MEDLINE, PsycINFO, the social sciences citation index and online African journals. The results were that, of 407 articles selected, 51 were eligible for qualitative analysis. Nineteen articles came from South Africa and the majority of 38 articles focused on HIV/AIDS [19]. End-of-life care was indicated as a major physical or social challenge for the guardians [19]. Sourcing appropriate food, medicines and water further exacerbated the poverty of the family members [19]. Funeral costs were reported to be one of the main concerns [19]. Additionally, time spent on caring for the patients implied less time for food and livelihood production and, at times, guardians had to sacrifice their own resources for the patients [19]. However, most African countries were not represented in this review, because almost 40% of the articles in this review were based on research conducted in South Africa [19].

The review above by Gysels et al is applicable in many countries in sub-Saharan Africa because it clearly focussed on the population of sub-Saharan Africa. The study design for a systematic review was appropriate because the relevant literature identified eight reputable electronic

databases. In addition, studies were assessed using a standard grading scale by the reviewers to identify relevant studies before including these in the review. The results of similar studies were combined. To combine the results of similar studies is deemed reasonable because all the studies were done in the same region of sub-Saharan Africa and all studies focussed on end-of-life care in sub-Saharan Africa. Some studies focussed on home-based care programmes, some on HIV/AIDS and some on culture.

The Gysels review showed that patients and their families face holistic challenges in terms of physical as well as psychosocial problems at the end of life. Malawi as a country did not contribute a study to this review, but the results of this review can be applied in a Malawian setting because Malawi is within sub-Saharan Africa and it has huge challenges in terms of HIV/AIDS, cancer and other non-communicable diseases. More evidence from this review can be found in the Malawi Palliative Care Policy that was introduced in October 2014 (although implementation of the policy has just commenced) [20].

The only limitation in the Gysels review is that 40% of the literature in this review came from South Africa.

Sankhe et al from India conducted a prospective, non-randomized, single-cohort study of 107 patients between September 2013 and September 2014 [21]. The study aimed to evaluate the role of spiritual care for cancer patients and their primary caregivers in terms of their spirituality and general well-being. Spiritual care was given under the MATCH guidelines. Two scales for measurement of quality of life of patients and their caregivers were used. The results showed that both patients and their families faced emotional, social and spiritual distress [21]. Nine patients out of 107 were lost to follow-up. The cause of spiritual distress was often that some patients believed that the cancer was a punishment from God and in a few cases patients lost their faith in the practice of spirituality [21]. Sankhe et al concluded that spiritual care increased the spiritual and general well-being of both cancer patients and their caregivers [21].

The results of the above study are applicable to all palliative care settings including Malawi because spirituality is one of the main components of palliative care. The study population of cancer patients and their guardians was appropriate for this cohort study. Sankhe's study showed

that cancer patients and their guardians found that spirituality was a way of coping with incurable illnesses. The scales that were used for measurement of quality of life of patients and their guardians were validated scales, which also makes the study more strong. Sankhe's study can be applied locally in Malawi because most Malawians value spirituality. However, Sankhe's study may not be fully applicable in the West because the majority of Western people may not value spirituality.

Sankhe's study design is deemed appropriate because the study population had the same characteristics. For example, they were all cancer patients and they were followed up for a specific period of time. However, Sankhe's study lacked the control group that could have increased the strength of the study.

The first principle of the MATCH guideline in Sankhe's study promotes a vegetarian diet because a meat diet reportedly contains carcinogens. The guideline opposes the killing of animals and states that a vegetarian diet has more antioxidants, which helps build cellular tissues. However, this researcher feels that the principle of a vegetarian diet is more applicable to the non-cancer patient population as a preventive measure and not for someone who has been diagnosed with cancer already, because cancer patients lose weight as a result of increased metabolism and they often have limited time to live. Diet alteration cannot change the prognosis at this stage.

Davison conducted a survey in 2008 in Canada relating to a university-based renal programme for end-of-life care preferences and needs and dealing with the perceptions of patients with chronic kidney disease [22]. The survey aimed to evaluate end-of-life care preferences for chronic kidney disease patients to help identify gaps between the then current end-of-life care practice and patients' preferences, and to help prioritize and guide future innovation in end-of-life care policy [22]. A total of 584 patients with stage four chronic kidney disease were recruited into the study. The study results showed that patients relied on the nephrology team for comprehensive end-of-life care needs [22]. The needs were pain and symptom management, advanced care planning and psychosocial and spiritual support [22]. Unfortunately, the needs were not systematically integrated into patients' renal care. Participants had poor self-reported knowledge of palliative care options, 61% of study patients regretted their decision to start dialysis and fewer

than 10% of the study patients had had a discussion about end-of-life care issues with their nephrologists in the past 12 months [22]. The strength of Davison's study was that it identified the gaps that existed between end-of-life care practices and patients' preferences. However, the study design should have been qualitative in nature with the aim of getting ideas from patients' perspective.

It must be mentioned that Davison's 2008 survey findings mentioned above were supported by Jassen et al in the same year. Jassen et al stated that patients with end-stage chronic organ failure experienced daily distressful physical and psychological symptoms, such as fatigue, pain, dyspnoea, coughing, lack of appetite, sadness and sleep disorders [23]. Walter conducted a study of cancer patients to identify special challenges faced by the patients in terms of cancer treatment and end of life [24]. Walter stated that moral and financial support were special challenges faced by patients in terms of cancer treatment and end-of-life care [24].

Garrido et al conducted a longitudinal study of patients with advanced cancer that determined the best set of predictors of psychological disorders, regrets, health-related quality of life and mental health function among bereaved caregivers of patients with cancer. From 2002 to 2008, patients and caregivers were recruited from outpatient clinics in Connecticut, Massachusetts, New Hampshire, New York and Texas. The results were that more than half of the caregivers reported regret about the type of care their patients had received at the end of their lives [25]. The conclusion was that reducing caregiver stress, promoting advanced care planning and having a good death appeared to be promising targets for interventions to improve caregiver bereavement [25]. These findings were supported by Kirchhoff et al, who described 'good' end-of-life care as ensuring that the patient is as pain-free as possible and that the patient's comfort and dignity are maintained [26]. It was further stated that involvement of the patient's family when planning end-of-life care is crucial [26].

Feely et al conducted a retrospective study about the prevalence and contents of advance directives for 841 patients with end-stage renal disease receiving dialysis from January 1, 2007, to January 1, 2012 at Mayo Nephrology Clinic and the Hypertension Clinic at the University of

Rochester. The authors found that only 3% of the participants in the study specifically addressed dialysis management at the end of life [27]. The experience from the study showed that there was no proper documentation of the end-of-life care values, goals and preferences, such as dialysis-specific advance directives, among the study patients [27].

It is not known whether patients' preferences and priorities for end-of-life care are discussed with patients at a later stage or are documented at Tiyanjane Clinic during clinic days or follow-ups.

Heckel et al conducted a qualitative study in Germany called *Effects of Methicillin Resistant Staphylococcus Aureas /Multiresistant Gram Negative Bacteria Colonization or Infection and Isolation Measures in End of Life on Family Care givers* [28]. The authors mentioned that family caregivers had suggested that healthcare staff should provide information to patients about their diagnoses, and not merely convey hygiene measures to patients[28]. It was further stated that family caregivers had asked not to be stigmatized due to the type of illness of the patient and instead they preferred to have psychosocial and emotional support after the diagnosis was made [28]. The limitation of Heckel's study was that the focus group discussion included three participants only. Fox in 2006 stated that a good focus group discussion should include approximately eight people with the aim of generating as many ideas as possible [29]. However, Fox pointed out that if the focus group discussion had more than 10 people it became difficult to manage the group [29]. The other limitation of Heckel's study was that the views of the patients themselves and the healthcare workers had not been sought, so then, rich information might have been missed.

In 2003, Murray et al performed two qualitative interview studies in developed and developing countries of patients and their carers relating to dying from cancer. One longitudinal study with qualitative interviews of 20 patients and their carers was conducted in the Lothian region in Scotland and one cross-sectional study with qualitative interviews of 24 patients and their main informal carers was conducted at Chogoria Hospital, Meru, in Kenya. Sixty-seven interviews were done in Scotland and 46 in Kenya. The findings of the two studies were at odds. It was found that the emotional pain of facing death was the main concern of Scottish patients and their carers,

whereas physical pain and financial challenges were the main concerns of Kenyan patients and their carers [30]. The conclusion was that end-of-life care experiences and the lived experience of the disease in developed and developing countries were different, and related to the availability of resources [30].

2.2 Information disclosure and life priorities

Innes and Payne conducted a systematic review in 2009 of advanced cancer patients' prognostic information preference [31]. Using a systematic review procedure, 13 studies were identified that addressed this issue [31]. The results showed that all patients wanted honesty from their professional team and the majority of patients wanted some broad indication of their prognosis [31].

The above findings were supported by Harding et al, who conducted a seven-country European population survey in 2013 of public preferences for disclosure of poor prognosis [32]. The study aimed to determine European citizens' preferences, within a scenario of serious illness such as cancer with less than a year to live, for information disclosure relating to poor prognosis, the likely symptoms and problems and the care options available [32]. A total of 9,344 participants were recruited into the study. The results showed that 73.9% of the study participants wanted to be informed in the scenario of having a serious illness such as cancer with less than a year to live [32]. A minority (21.1 %) did not want such information [31]. Participants with past experience of illness and with more education were more likely to want to know about limited time left [32].

Buckman stated that communication is the best part of cancer care [14]. This was supported by Fujimori et al, who conducted a survey in Japan that aimed to establish patients' preferences regarding the breaking of bad news in the clinical oncology setting [33]. A total of 529 cancer patients were recruited into the study. The results showed that more than 90% of the patients were willing to discuss the treatment options that were available at the time, 50% of the patients wanted to know their life expectancy and 30% did not want to know their life expectancy [33]. The survey revealed four preference factors: The method of disclosure of bad news; provision of emotional support; provision of additional information; and setting [33].

Zafar et al conducted a survey of 520 patients at Shaukat Khanum Memorial Cancer Hospital and Research Centre situated in Lahore, Pakistan. The study aimed to survey preferences of cancer patients regarding the disclosure of diagnosis and life expectancy. The results were that three in five study participants wanted a healthcare staff member to provide them with comprehensive information about their prognosis and life expectancy [34]. Those study participants who did not want to know more about their prognosis and life expectancy were more likely to be females and had a lower socio-economic status [34]. Two out of five study participants expressed the wish to die at home [34]. Zafar et al concluded that the majority of the participants preferred an honest disclosure about their disease diagnosis and expressed a choice of hospital-based care at the end of life [34]. The strength of Zafar's study was that it used both quantitative and qualitative methods. A questionnaire and a semi-structured interview guide were used to collect data. The weakness of Zafar's study was that it used a questionnaire that had not been validated previously.

Nishi et al conducted a retrospective study in Japan of 248 patients and their families between April 2013 and March 2016. The study dealt with the disclosure of survival prediction to the patients who had been referred for first review to the palliative care department. It was found that 43% of the patients and their families had received information about the prognosis before their referral to the palliative care department [35]. However, 19% of the patients and their families had not been told about their life expectancy by their previous doctors [35]. What is not known is the level of absorption and retention of bad news about the terminal diagnosis by the patients and their families during the initial disclosure of the cancer diagnosis, where this had taken place.

Cao et al conducted a survey about the relationship between perceived initial cancer disclosure communication with physicians and the levels of hope and of trust among 192 cancer inpatients in a cancer hospital in China. The findings of the survey showed that patients whose conditions had been disclosed by family members may have had higher levels of hope and trust than patients whose conditions had been disclosed mainly by physicians [36]. Cao et al concluded that physicians might have ignored the significance of emotional support during the cancer diagnosis disclosure [36].

Cao et al recommended that family involvement and collaboration were vital during the cancer diagnosis communication and discussion of treatment options and advanced care plans [36]. However, Hagerty et al in 2005 argued that prognosis was an issue that most doctors and patients described as difficult to discuss and it was not clear what the best way was to present prognostic information to maximise patients' understanding, psychological adjustment and decision-making [37]. In addition, Kiely et al in 2010 argued that, although the literature recommends that patients need to be given prognostic information in a meaningful and realistic way, while hope is maintained at the same time, healthcare professionals struggle to find suitable answers when applying this principle in practice and when confronted by versions of "how long have I got?", because the time of death is uncertain. [38].

2.3 Decision-making

Davison et al conducted a European population-based survey with 9,344 adults in England, Belgium, Germany, Italy, Netherlands, Portugal and Spain from May to December 2010 [39]. The survey aimed to examine public preferences relating to self-involvement through a living will in end-of-life care decision-making and to identify associated factors. The results showed that 74% of the participants preferred self-involvement when capable and 44% preferred self-involvement when incapable [39]. However, it was found that those participants who preferred to be involved had attained higher education levels and were females, while those participants who suffered financial hardship and who preferred to die in hospital were less likely to prefer self-involvement [39].

In contrast, Downing et al, in a survey conducted in Kenya in 2014 in relation to decision-making about-end-of life care, reported that 47.8% of the survey participants had wanted to be involved in decision-making at the end of life if they had the capacity to do so [40].

Hsieh et al conducted a retrospective cohort study of 368 patients who had passed away in a surgical neural intensive care unit in Taipei, Taiwan, over a period of three years. The study aimed to examine the relationship between surgical intervention and the willingness of patients and their families to donate tissue after withdrawal of life-sustaining treatment. Twenty-eight

patients out of a total of 368 patients had had life-sustaining treatment withdrawn [41]. Fourteen patients had had surgical intervention and had been admitted because of neurocritical conditions [41]. Hsieh et al concluded that patients who underwent surgery and had a good disease understanding together with their families had a higher probability of donating tissue after withdrawal of life-sustaining treatment [41]. Families of patients who had not donated tissue had reported that they had not had enough time for end-of-life care discussions for them to have made an informed decision. The main learning point in Hsieh's study is that end-of-life care discussions should be started early, so that patients and their families have enough time to absorb and retain the information.

2.4 Place of care

Tapsfield and Bates conducted a six-month review of case notes from all inpatients seen at Tiyanjane Clinic for palliative care, Blantyre, Malawi, from April to September 2009 [42]. The review evaluated a hospital-based palliative care service. The results showed that a total of 177 patients, about whom 137 case notes were available, had been seen during that period. Sixty-five per cent of the patients had been discharged to go home and 26% of the patients had died during admission [42]. Pain was the most commonly reported symptom in 74% of the case notes; 42% of the cases had HIV-related conditions, 48% had non-cancer conditions and 9% had palliative care diagnoses [42]. However, the above review did not specifically address the challenge of preferred place of care, because the patients had not been interviewed to establish whether home was really their preferred place of care. It was also not mentioned in the above review whether some of the patients who had been discharged had come back for another admission. A prospective study would have helped to follow the patients and document what actually happened to the patients after discharge.

Higginson and Sen-Gupta conducted a systematic literature review of the preferences for place of care and of death among advanced cancer patients [43]. The authors concluded that home care was the common preference, with hospice care as second preference in advanced cancer cases [43]. Similar findings were reported by Merriman in Uganda in 2006 and Grant et al in Kenya in 2003

[44, 45]. However, despite having home support from family members, patients' physical needs in these cases were not being met in either Uganda or Kenya because patients were dying in pain.

Kikule conducted a survey of the palliative care needs of terminally ill people in urban areas in Kampala, Uganda, from January to April 2000 [3]. The study aimed to identify the palliative care needs of terminally ill patients across Uganda. A total of 173 terminally ill patients were registered with home care programmes. The majority of the study participants had either HIV/AIDS or cancer or both. A total of 145 study participants were under 50 years of age and 107 were women. At the time of the study, there were home care programmes in and around Kampala that looked after terminally ill patients in their homes [3]. The results showed that three main needs had been identified: Control or relief of pain and other symptoms; counselling; and financial assistance for basic needs such as food, shelter and school fees for patients' children [3]. The preferred place of care was home; however, all patients lived in urban areas within 5kms from the healthcare facility and therefore had access to healthcare services.

The design of the above mentioned study conducted by Kikule was appropriate. Kikule's study was a survey that aimed to identify palliative care needs and the best approach for Kikule's study was a quantitative approach. The sample size in Kikule's survey was calculated so that the results could be generalised in the study catchment area. The study results were valid and can be applied in urban areas that have functional home care programmes. However, Kikule's findings cannot be applied locally in urban Blantyre, Malawi, because in the city of Blantyre only two locations (Bangwe and Ndirande) have home-based care programmes, supported by the College of Medicine Project and the Palliative Care Support Trust. Furthermore, Kikule's findings cannot be applied in rural or in hard-to-reach areas in Malawi where patients have to travel long distances to access healthcare services. Patients may opt for hospital care because of transport expenses, as some palliative care patients may be bedridden, which would require hiring a car. The study population in Kikule's study was from the urban areas of Kampala and the needs of the rural population may be different. The other limitation of Kikule's survey was that it examined patients' needs only during the time it took to conduct the study; however, Gomes et al in 2011 argued that patients' preferences may change as the illness advances [46].

2.5 Place of death

Gomes and Higginson conducted a systemic review in September 2004 of all previous studies that had aimed to determine factors that influenced death at home in terminally ill patients with cancer. Four electronic databases were searched, namely Medline (1966-2004), PsychINFO (1972-2004), CINAHL (1982-2004) and ASSIA (1987-2004). The authors found that 58 studies met the inclusion criteria, with a total of over 1.5 million patients from 13 countries. The results showed that 17 factors were associated with home death [47]. Among the 17 factors identified, only six factors were strongly associated with home death [47]. Factors related to illness, like low functional status, were associated with home death [47]. Demographic variables of patients, like high levels of education, high social class and high income, were associated with home death [47], as were the availability of social support at patients' homes [47].

Uwimama and Struthers conducted a study in 2008 in Rwanda about the preferred place of care at the end of life for HIV/AIDS patients in countries affected by civil war and genocide [48]. The study investigated where HIV/AIDS patients wished to be cared for at the end of their lives [48]. The results showed that the majority of patients wanted to be cared for and die in hospital [48]. The probable explanation might be that most of the patients had no relatives available in their homes since many of the relatives had been killed during the civil war and genocide.

Downing et al conducted a population-based street survey about public preferences and priorities for end-of-life care in Nairobi, Kenya, in 2014 [40]. The survey aimed to explore public preferences and priorities in Nairobi. A survey questionnaire that was adapted from a European survey questionnaire was used. A total of 201 participants representing 17 tribes were recruited into the study. The results showed that 51.1% of the study participants preferred to be cared for and to die at their homes, 56.7% preferred to receive prognostic information, and 61.4% preferred quality of life over quantity [40]. The three main concerns of the study participants were pain (45.8%), family burden (34.8%) and personal psychological stress (29.8%).

The strengths of the Kenyan survey were the following: An appropriate research design was used. This was a quantitative study in which a survey questionnaire was used. The survey questionnaire was valid because it had been adapted from a version of the PRISMA European

questionnaire, which had been tested before. The study results of the Kenyan survey can be applied locally in the city of Blantyre, Malawi, because the cities of Nairobi and Blantyre are both urban areas. The weaknesses of the Kenyan survey may include the following: The study aimed to explore public preferences and priorities for end-of-life care in Nairobi; however, if the research set out to explore something in detail, a qualitative approach was necessary. The Kenyan survey recruited only those participants who were able to speak the English language, omitting the views of non-English speakers. The sample size of this study was 200; however, the population of Nairobi was not given, so that the sample size could not be confirmed as representative. The other limitation is that the Kenyan study was done in an urban area where the public had good access to home-based care services, unlike rural areas of Kenya. The study population in the Kenyan study was the public and not the patients. It might have been better to explore the preferences and priorities of patients themselves concerning end-of-life care in Kenya.

Gerrard et al conducted an audit in 2007 and repeated it in 2009 at St. George's NHS Trust. St George's NHS Trust is a large London teaching hospital and it has a joint cancer centre with Royal Marsden Hospital. The audit examined discussions about preferred place of care with all patients who had been referred to the hospital palliative care team and who had passed away during the audit period. The results showed 236 and 275 recorded deaths in 2007 and 2009 respectively. The results were that patients who had preferred to die in hospital had increased from 10% to 30% during the audit period [49]. Many patients had expressed the wish to die at home, but the majority had died in hospital [49].

Similar findings were reported in several studies by Munday et al in 2007, Gomes and Higginson in 2008, Gomes et al in 2013 and Pollock in 2015 [50, 51, 52, 53]. However, Pollock in 2015 argued that focussing on the place of death is not an over-riding priority, but control of pain and other symptoms and being accompanied by loved ones are more important to dying patients, and it does not matter whether the patient is at home or in hospital [53]. Gerrard et al concluded that there was a need to differentiate between the preferred place of care and preferred place of death.

Edmonds and Rodgers conducted a review of care of patients dying in an inner-London teaching hospital. One hundred and eighty-two informants were invited to participate in the study. Of the 182 participants, 78 returned completed questionnaires. The results were that half of all patients had died in hospital, despite the availability of palliative care in the United Kingdom [54]. However, Edmonds and Rodgers reported that guardians of bereaved families had stated that care given to patients at the end of their lives in the hospital had been poor [54]. The reasons given were the following: Lack of open communication about the prognosis and lack of advanced care planning; and the fact that nurses focussed only on meeting patients' physical needs in the hospital without addressing their psychological and spiritual needs [54]. In addition, Edmonds and Rodgers reported that there was a practice of distancing and isolating patients by healthcare staff as death approached; as a result, effective communication was prevented [54]. The limitation of the above study was that fewer than 50% of participants who had been invited to participate in the study had completed the study questionnaire, and it had excluded participants who were unable to read and write in English. However, the Choice in the End of Life Care Programme Board in London stated in 2015 that, if they were to make deaths at home more achievable, they had to do more to ensure sufficient support for those paid carers who might be vital in sustaining the viability of care at home [55] .

In a cross-sectional descriptive study by Widger et al conducted in Canada in 2012, the authors reported that there had been an increased proportion of deaths in critical care settings over time and that a lower proportion of deaths was occurring at home [56]. The authors further reported that parents of dying children were less inclined to choose home as a place of death because of a fear of isolation and inadequate care [56]. However, even if the family had chosen home as preferred place of death for their dying child, not all regions in Canada were able to offer home care for some children who had multiple medical challenges at the end of life [56]. It was further reported that adults in Canada had been opting for an inpatient hospice or palliative care unit as a third option apart from home and hospital, because an inpatient hospice and palliative care unit were able to provide specialized physical, psychological, social and spiritual care at the end of life [56].

2.6 Conclusion

Literature reviewed showed that patients experience physical, psychosocial and spiritual challenges at the end of their lives. Many studies showed that patients want to know their prognosis. Some patients regret their decisions because of inadequate information they have received from the healthcare staff. Discussing end-of-life care issues is regarded as a taboo subject globally. The result is that end-of-life care discussions are not initiated by healthcare staff. The preferred place of care and of death varies from country to country. However patients' preferences and priorities change as the disease advances. Home is regarded as the most preferred place of death. However, the current data shows that home deaths are reducing in number and hospital deaths are increasing in number, despite the availability of resources such as hospices and nursing homes in Western countries.

3.0 Chapter Three: Methodology

3.1 Introduction

The researcher decided to conduct the study about patients' preferences and priorities for end-of-life care at Tiyanjane Clinic for palliative care at the Queen Elizabeth central hospital in Blantyre, Malawi. This study explored patients' preferences and priorities relating to end-of-life care that could serve as a catalyst for uncovering unknown concerns that create fear in patients at the end of their lives. The extent to which the unknown concerns affect the patient's journey towards the end of life is not clear. The study intended to listen carefully to palliative care patients in Malawi to discover how they understood their illness, viewed their own involvement in decision-making and how they felt their individual care could be tailored for them at the end of their lives.

3.2 Rationale of the study

This research study sought to conduct evidence-based research on patients' preferences and priorities for end-of-life care in Malawi to add to the limited availability of such research in the country.

3.3 Aim of the study

This study aimed to explore preferences and priorities for end of life care experienced by adult patients with a terminal diagnosis.

3.4 Objectives of the study

1. To explore current knowledge, thoughts and gaps of information that patients experience about end of life care.
2. To assess how much information patients would like to be given about their illness
3. To assess patients' choices in terms of their being involved in healthcare decisions
4. To determine patients' willingness and level of comfort in discussing end-of-life issues
5. To investigate whether patients had a preferred place of death.

3.5 Study design

This was a qualitative, descriptive study which explored preferences and priorities for end-of-life care as experienced by adult patients attending Tiyanjane Clinic, QECH, Blantyre, Malawi. Qualitative approach was used in this researcher's study because the researcher wanted to explore preferences and priorities based on patients' perceptive. Data then emerged from the participants and was not imposed by the researcher. For example, how different patients, look differently at preferences and priorities for end of life care.

3.6 Study site

The study site was Tiyanjane Clinic for palliative care, which is a government clinic located in QECH, Blantyre, Malawi. The clinic is within the Department of Medicine at the University of Malawi. The study site caters for a broad range of patients referred to the Clinic from wards, other clinics, health centres and district hospitals in the southern region of Malawi.

3.7 Study population

An equal opportunity to participate in the study was provided to all adult patients diagnosed with life-threatening illnesses and receiving palliation at Tiyanjane Clinic.

Inclusion criteria:

Participants who:

-were able to communicate fluently in English or Chichewa,

-were adults aged 18 years and above

-were ambulatory, required occasional assistance, but were able to take care of most of their needs, or patients who were fully active [57].

Exclusion criteria:

Participants who:

-were too ill to participate

-when assessed by the researcher and palliative care team, were considered to be either mentally or emotionally incapable of participating. Patients who were unable to effectively communicate or had diminished decision-making capacity were assessed on the basis of their disorientation in terms of place, time and person.

3.8 Sample size

The study purposively sought to recruit between 10 and 14 participants until data saturation was reached.

3.9 Sampling method

The study purposively sought to recruit between 10 and 14 participants until data saturation was reached. Purposive sampling was appropriate for the study, as it enabled the researcher to identify from the onset those participants with similar qualities, which fitted the requirements of the study [58]. The rationale behind purposive sampling was to select patients who would provide detailed information regarding end of life care after being diagnosed with a terminal illness. Those patients who had no confirmed diagnosis but were receiving care at Tiyanjane clinic were not approached. Some patients still get care from Tiyanjane clinic while they are being investigated. For example patients with severe pain but are waiting for histology results. The balancing was done by approaching all patients who had a confirmed diagnosis at the clinic.

3.10 Data collection

Data was collected using two collection tools. The first one was a demographic data collection sheet. This was used with the aim of collecting demographic details direct from patients' records. The second collecting tool was a semi-structured interview guide (Appendix 4).

3.11 Data collection tools

Data was collected by conducting semi-structured face-to-face interviews. A semi-structured interview guide was developed, using open-ended questions to steer the flow of the interview. The open-ended questions had a bearing on the research title. The guide was developed by the researcher on the basis of the literature guide that was reviewed in Chapter One, after

consultation with the research supervisor and co-supervisor. The first part of the interview guide consisted of an opening statement of thanking the study participant for choosing to take part in the study, acknowledging the sensitivity of the research title, and ensuring the participant that the conversations would be kept confidential and were for the researcher's academic purpose only. The second part of the guide consisted of eight questions that related to the research title.

An audio tape-recorder was used to capture data, which was transcribed *verbatim.* The transcription and translation from Chichewa to English of the audio interviews were done by an independent person. Another independent person again translated the transcripts from English back to the Chichewa language, in order to compare whether what patients had said was really reflected in the translations.

Permission was sought from the study patients to get demographic data from their clinic files. Demographic data was extracted from existing patient files within Tiyanjane Clinic and they were entered into the demographic data sheet. The reason for collecting demographic data was to establish patients' social, education, and economic status. In addition, patients' tribes, districts of origin and current place of residence were established in the demographic data.

During the interview, the researcher took field notes of any observations, cues, behaviours and interruptions that came up during the interview. A separate room where there would be no disruptions was identified for conducting interviews.

Triangulation of data

Apart from the interviews which were conducted, the researcher also observed and documented the behaviour of the participants during the interviews. For example, emotions which were observed from some participants were observed and documented during the interviews. In addition, the research supervisor read all transcripts just to compare the emerging themes which the researcher came up with from the transcripts. Furthermore, the co-supervisor of the research listened to some audio interviews of the participants and read the transcripts just to appreciate the emerging themes from the data.

Credibility and Trustworthiness of the study

During the process of developing and reviewing the interview guide, the researcher applied guidelines from the literature as well as sought input from colleagues and supervisors. That enhanced the knowledge and skills of the researcher. The aim of credibility and trustworthiness was to make sure that the semi-structured interview guide was asking the correct questions and that the semi-structured interview could collect similar data if used at a different site with another group of patients. The principles of credibility, dependability, confirmability and transferability ensure trustworthiness of the data in qualitative research.

3.12 Data collection procedure

The study commenced after approval had been obtained from the University of Cape Town Human Research Ethics Committee (UCT HREC). Permission to conduct the study was also sought from the College of Medicine Research Ethics Committee (COMREC), the Hospital Director of QECH and the Medical Director for Palliative Care Support Trust (PCST).

The researcher listened to the recorded data and compared that with the transcripts to make sure that the translation reflected what the patients had said. Next, one of research supervisors listened to a few recorded interviews and compared those with the transcripts to make sure that what was in the transcripts reflected what the study participants had said.

(i) Study introduction

The researcher then set up a meeting with the Head of Tiyanjane Clinic to discuss study logistics. The researcher introduced the research study to the whole palliative care team at Tiyanjane through a presentation. Due to the sensitive nature in which conversations were to be conducted with that vulnerable group, the researcher - who is an experienced palliative care professional - personally conducted one-on-one interviews with participants.

(ii) Training research assistants

The research assistants were trained for a half a day. The meeting was held in the afternoon in the medical annex library. There were two research assistants. The first assistant's duty was to

introduce the study to the participants and explain what the research was about. The second research assistant's duty was to get consent from the study participants. The research proposal was presented to the research assistants.

The training covered the rationale of the study and ethical issues, including patient confidentiality, protection from harm in terms of disclosure and the need not to persuade patients to participate in the study. It was emphasized to research assistants that all patients had to be told that their participation was voluntary and that their refusal to take part in the study would not compromise the care that they received from Tiyanjane Clinic. The last part of the training covered aspects of how to administer the consent form to the study participants. The research assistants were bilingual in Chichewa and English.

(iii) Recruiting participants

To recruit participants, a research assistant was identified and trained to eliminate any bias in the recruitment process. The research assistant was a trained palliative care nurse with good communication skills. The research assistant ensured that patients were aware that a researcher (and not the research assistant) was to conduct the interview. Study information sheets and consent forms had been developed and were used to recruit participants.

The duty of a palliative care nurse was to help screen the patients in order to find out who was eligible for the study. An independent person who was experienced in research and not involved in the usual care of the patients obtained consent from the patients. The aim was that patients should be able to make informed choices without being influenced by the nurse who was involved in the usual care of the patients.

The research assistant approached and introduced the study to the eligible participants. Thereafter, individuals who were willing to hear more about the study were identified. Willing participants received treatment first before being taken to the interview room within the Clinic.

The research assistant provided and explained the study information sheet and consent form to each participant. Thereafter the participant was given time to ask questions. Once the participant was satisfied that all questions had been answered, the participant was referred to

an independent person who was experienced in research to sign a consent form. The recruiting process, including a discussion of the data information sheet and consent form, was conducted in the participant's preferred language. On completion of the recruitment process, the research assistant called and introduced the participant to the researcher, who thereafter conducted the interview. There was no additional burden to patients because no other research was being done at Tiyanjane Clinic. The approximate length of the interview was 30 minutes.

(iv) conducting interviews

The researcher requested a private room within the Clinic for conducting the interviews. That was to ensure that the interviews were conducted in a familiar environment with no disruption to the patient's routine. A well-ventilated room was used for the interviews. Participants were each provided with a bottle of water. The participants were allowed to stop the interview at any time once they felt tired. If the participant wanted to continue the interview on another day, the date and time were arranged to finish the interview. The study commenced once all the mentioned measures were in place.

3.13 Data storage

The data and recordings were stored in a lockable cabinet to which only the researcher had access. The data included audio and hard copies of transcripts as well as field notes. To ensure that confidentiality was maintained, audio data collected from recorded interviews was stored in password-protected computer files.

3.14 Data analysis

A thematic framework was used to inform the systematic approach to data analysis. The researcher used thematic analysis because the study was a qualitative and descriptive in nature. For example, what was specially said by the participants and observed and documented by the researcher during the interviews. The researcher paid attention to data emerging from participants by identifying frequency of words or phrases mentioned and grouping them into

themes and sub-themes. Themes and sub-themes were then collated thus providing rich data provided by the participants which informed findings of this study findings.

The researcher familiarized himself with the data by reading it several times. Then the researcher identified themes which emerged from the data by reading all the transcripts line by line. Emerging themes were identified by underlining them in each transcript and grouped into named categories. Thematic analysis begun in parallel with the interviews so that the researcher could discover and incorporate new themes as the study was going on. The reason was that the researcher wanted to include some of the things like emotions which were observed during the interviews. Themes were then coded and broken down into sub-themes [59]. The research supervisors listened to some of the interviews and analysed the data to ensure that there was consistency in the coding and to eliminate bias.

3.15 Ethical considerations

The study commenced once approval had been obtained from the UCT HREC and permission to conduct the study had been granted by the COMREC.

Confidentiality was upheld by informing participants that any information provided would not be used for any purpose apart from the researcher's academic interest. The researcher was a student. That was the only reason why the researcher wanted to do the research study. The research was part of the fulfilment of the researcher's master's degree.

Autonomy was promoted by giving participants permission to stop the interview at any time if they experienced any distress. Participants could withdraw from the study at any time without explanation and such a decision would not compromise the quality of care they were receiving at Tiyanjane Clinic. Participation in the study was voluntary and this was stated in an informed consent form, which all participants signed.

3.16 Distress protocol

Emotional support was available to address any distress that was being experienced by participants. A documented distress protocol was arranged by the researcher with the

Tiyanjane palliative care team. If, during the interview, a participant displayed or expressed physical or psychological distress, then he/she was allowed to stop the interview or the researcher used his own discretion to do so. An opting out question had been included in the interview guide to ensure that each participant was afforded the choice to either abandon or continue with the interview process.

One patient appeared distressed, the interview was interrupted and the distress protocol was followed (Appendix 3). The patient was asked, 'Would you like to stop the interview now?' She answered that she would like to stop, and the interview was immediately ended. The patient was referred to the Tiyanjane palliative care counsellor but she refused. The researcher gave the study participant an opportunity to come back at any time to continue the interview but she never came back.

4.0 Chapter Four: Results

4.1 Introduction

The researcher conducted a qualitative study that focused on an exploration of patients' preferences and priorities for end-of-life care at Tiyanjane Clinic for palliative care, Queen Elizabeth Central Hospital, Blantyre, Malawi. The researcher conducted face-to-face, cross-sectional, semi-structured interviews with the help of a topic guide to collect data from 14 patients. One participant declined to join the study because of the sensitivity of the topic and time constraints. The researcher reached data saturation by the 13th participant when no new themes and sub-themes were emerging. The data collected from these interviews is reported in the form of this chapter narrative approach. Themes and sub-themes developed during the process of coding will be presented and supported by important quotes from the semi-structured interviews that were conducted.

4.2 Demographic data of study participants

The participants were six males and eight females. The interviews were conducted at Tiyanjane Clinic. The participants were suffering mainly from Kaposi sarcoma, tuberculosis, cervical cancer, rectal carcinoma and HIV. Twelve participants had a diagnosis of Kaposi sarcoma with other comorbidities like HIV and tuberculosis. The interviews were conducted over a period of one month. The first interview was conducted on 14 December 2016 and the final interview was performed on 18 January 2017. The average time of each interview was approximately 23 minutes, with the shortest interview being about 14 minutes and the longest interview being about 34 minutes.

4.3 Themes

Eleven themes emerged from the interviews and are shown in the table below:

Themes and sub Themes

Themes	Sub-themes	Definition	Index Code
1. Awareness of reason for being at Tiyanjane	1.1 Pain relief	Stating the importance of pain relief as one of the essential physical aspects as mentioned in WHO definition of palliative care.	1.1
	1.2 Effective treatment	Acknowledging the results of treatment received at Tiyanjane Clinic	1.2
	1.3 Receiving essential palliative care drugs	Mentioning the importance of drug availability as one of the essential components in the provision of palliative care as stated in the WHO Public Health Strategy for palliative care.	1.3
	1.4 Medical resources	Highlighting lack of essential medical resources such as radiotherapy.	1.4
2. Reluctance to mention HIV	2.1 HIV discussion	Difficult and very hard to discuss HIV but easy to discuss cancer.	2.1
3. Psychosocial concerns	3.1 Financial support	The need for financial support after being diagnosed with an incurable illness	3.1
	3.2 Acceptance	Accepting the diagnosis of an incurable illness	3.2
	3.3 Loss of independence	Feeling lonely when guardians are busy with other things	3.3

	3.4 Isolation	Being a burden to others, therefore reluctant to ask for assistance	3.4
4. Expressed emotions	4.1 Worries	The dominant emotion expressed after being diagnosed with an incurable illness	4.1
	4.2 Sadness and tears	Feelings observed during the study period	4.2
5. Legacy	5.1 Last wishes	Need to have an opportunity to express one's last wishes	5.1
	5.2 Will writing	Recognising the need to leave a will after one has died to avoid property grabbing	5.2
	5.3 Care of the children	Concern about who is going to look after the children.	5.3
6.Receiving of information	6.1 Need for more discussion	Openness to engage in discussion and receive more information	6.1
	6.2 Unwillingness to receive more information or discuss end-of-life issues	Not willing to know more prognostic information about the diagnosis when the expected news is bad	6.2
	6.3 Willingness to discuss end-of-life care issues	Expressing the wish to discuss end-of-life care preferences	6.3
7. Decision-making	7.1 Willing to be involved	Expressing the wish to be involved in decision-making about available care options	7.1
	7.2 Not willing to be involved	Choosing not to be involved in decision-making about available care options	

			7.2
8. Place of care	8.1 Hospital care 8.2 Home care	Hospital as a preferred place of care Home as a preferred place of care	8.1 8.2
9. Place of death	9.1 Hospital death 9.2 Home death 9.3 Difficulties in expressing the preferred place of death	Hospital as a preferred place of death Home as a preferred place of death Difficulties in being precise in predicting the actual place of death	9.1 9.2 9.3
10. Spiritual concerns	10.1 Prayer and faith 10.2 Religious rituals 10.3 Traditional healers	Importance of prayer and faith in dealing or coping with incurable diseases Fulfilling religious rituals before the occurrence of death Individual opinions in relation to seeking help from traditional healers	10.1 10.2 10.3

Theme 1. Awareness of reason for being at Tiyanjane

Most participants stated that they were aware of the reason they had been referred to Tiyanjane Clinic.

1.1 Pain relief

Most participants stated that pain control had been a priority for their admission.

'I don't feel pain anymore as it was at first.' (P004)

'I couldn't sleep at night but when I started taking injections I saw changes and the pain is gone.' (P007)

'I had joint pains in my knee and hip…. my pain improved after receiving radiotherapy in India…. within 10 days when I started radiotherapy all the pain was gone ….' (P011)

'They were giving painkillers to relieve the pain because I was feeling very painful.' (P014)

1.2 Effective treatment

Most participants mentioned that treatment received at Tiyanjane was effective.

'My appearance has changed completely.' (P004)

'…now I have started the medication it is really helping, I can see so much change compared to when I came at first because I couldn't walk they used to carry me on a wheelbarrow.' (P005)

'I can see changes since I started taking medication……I really see that my leg is improving now because it was swollen, I was failing to walk or even sitting down… I can see more changes and I have a healthy and good life even if I haven't finished my dose.' (P006)

'At first they gave me injections and I can see that this the treatment has helped me a lot and I can see and feel the change.'(P007)

1.3 Receive essential palliative care drugs

Some participants highlighted how essential medication had run out of stock when they needed to get it.

'… but when I came to start the injection they had run out of stock for injections.' (P006)

'I was told that drugs were out of stock. I have been going there several times just to check if drugs were in stock but to no avail. I was advised to come and check with Queen Elizabeth Central Hospital if the drugs were available. The first time I came to Queen Elizabeth Central Hospital the cancer drugs were out of stock as well for many months.' (P008)

'These medications are very expensive……And they should be readily available…Sometimes we are told you to bring MK100, 000.00 (142 US dollars) when coming for chemotherapy then we are directed to the specific pharmacy where such a drug can be bought.' (P011)

'The doctor told me to go and buy vincristine because it was out of stock here at the hospital; they even gave the name of the pharmacy which I could buy the vincristine in Blantyre.' (P013

1.4 Medical resources

Some participants mentioned that Queen Elizabeth Central Hospital lacked many resources.

'Before I had a small operation where they did a biopsy which I was told to go with to the College of Medicine where I paid K1, 500.00 because QECH could not do histopathology services.' (P001)

'Most people die at QECH because of lack of resources….. When you reach that stage, you fail to breathe properly and there is need for oxygen which is not available at home… You know your job as clinicians and doctors but you don't have required resources to help you to assist us accordingly…. So I managed to go for radiotherapy in India because there is no radiotherapy here in Malawi…..There is only one MRI (Magnetic Resonance Imaging) machine in this country. I t is only available at QECH.' (P011)

Theme 2. Reluctance to mention HIV

2.1 HIV discussion

Most participants were open to discussing cancer but all found it difficult to discuss HIV.

*'I think the doctor explained to me that I have cancer**...**My wife will explain everything about my illness……She is also on ARVs and vincristine.'(P001)*

'I am really affected by this cancer, I could have done something with my life but I fail to do anything because of this problem.' (P002)

'It is true that I am ill, this sickness started with itching of my leg and then when I came here at the hospital, I was examined by doctors and they told me that I have skin cancer.' (P006)

Theme 3. Psychosocial concerns

3.1 Financial support

Most participants were concerned about the financial constraints their illness has caused.

'…I am talking about transport costs… without troubling people to pick you with a car which is also expensive.' (P005)

'As of now I depend on other people for help which makes me wonder that will my life be like that depending on someone…..Yes from food to transport money for me to come here, I am being assisted by well-wishers. …then you think of the hustle for family members to find transport money for taking the dead body from the hospital to home' (P006)

'I was lucky I have children who contributed money for me to go there but there is someone out there who can't even find a tambala to go to India….. A person who comes from the village cannot afford which is very disappointing.' (P011)

'I do not work. I was only depending on him for financial support… I find it difficult to get daily food for me and the children….I don't have relatives who can help me…there is no one to look after me and the children…. (P013

3.2 Acceptance

'…if they tell that you have been diagnosed with this, learn to accept the situation and move on.' (P011)

'The information which they gave was to accept that I have this disease' (P014)

3.3 Loss of independence

Some participants expressed the feeling of loneliness when guardians were busy with other things.

'…when I come here for review I am being encouraged and I tend to forget these problems rather than when I am at home alone.' (P001)

'It is because there is a difference between home and hospital. At home people are always busy with their work while at the hospital, doctors and nurses are busy with patients.' (P003)

'At home, family members will just lock you up in the house and leave you alone because they are busy with other things like gardening.' (P006)

'The guardians are just there to watch, they can't do anything.' (P013)

3.4 Isolation

Some participants expressed deep concern about being a burden to guardians.

'…at home guardians stop doing their daily jobs because they are busy caring with you.' (P001)

'When you are suffering from this disease, it involves many people around you. For example, when you become very ill, you have to find someone to assist you with transport money to the hospital.' (P005)

'As of now I depend on other people for help which makes me wonder that will my life be like that depending on someone.' (P006)

Theme 4. Expressed emotions

Different emotions were expressed by participants after being told that they were suffering from incurable illnesses.

4.1 Worries

This was the most significant emotional response shared by all participants.

'I am also worried that I might be sacked out of the job because of my absenteeism. This is making me miserable.' (P005)

'I was worried about this disease that if it continues like this that means I may be paralyzed and there was no future for my wife and children.' (P007)

'I have so many worries….. We have children but he divorced me and kept on marrying several ladies in town….. What worries me most is when I think about that time I will be very ill.'(P013)

'I have worries mainly concerning my children that I can't work to give them help as I was doing in the past…I am worried because of their care in future.' (P014)

4.2 Sadness and tears

The researcher observed that two participants expressed emotional pain during the interviews. Their facial expressions changed and they shed tears. However, they never stopped talking.

Theme 5. Legacy

Some participants expressed the wish to leave a good legacy.

5.1 Last wishes

Some participants had last wishes.

'When I will be about to die, what I want is that all my belongings should be given to my children not anyone else so that they should remember me as they grow up that they had a father.' (P001)

'I wish I would have retired and get my benefits….my benefits from work and my property should be given to my children and other relatives' (P005)

5.2 Will writing

Some participants expressed the wish to leave a will after death.

'I have thought about writing a will…. I am supposed to build a house at both my village and my wife's village…… Everything which I bought in the house I will leave them for my children, there is nothing for my relatives…..the doctors should explain everything about my will even if it is in court they will be told how I need my worthy to be distributed.'(P001)

5.3 Care of the children

Some participants expressed concern about the care of the children.

'Actually most of the times when I am sick everything becomes at a standstill because I have children who look up to me for support…. I am worried about my wife and children because if I can die there will be no one to support them.' (P001)

'..To have strength and work again to help my children reach mature level…… I will not be happy to die earlier and leave my little children…..So I try very hard to follow and take whatever the

doctors give me and work for maybe two or three years so that at least when I will be dying my kids should be somewhere.' (P004)

'They should remember that I have a kid who depends on me; they should look after him properly because I will not be able to assist him. What happens most of the times is that orphans are neglected and abused.' (P010)

Theme 6. Receiving of information

6.1 Need for more discussion

Most participants were open to engaging in discussion and receiving more information.

'I will be very flexible for you to explain to me more about this disease…..I am very free to listen to what we can discuss.' (P001)

'I would have loved if there was a another way of helping us apart from giving us treatment, there should be another place for us to talk about other issues concerning our lives, that place which we use to receive treatment is good for the doctors to call us and hear our problems whereby we can freely express our feelings.' (P002)

'I will be very happy because I will know the truth about the disease…. Once I know where my problem is coming, the truth will set me free.' (P008)

'I would like to know more because they did not explain to me but I am very willing to know.' (P012)

'It is better to be told about the illness and the expected outcome and be told what to do.' (P013)

6.2 Unwillingness to receive more information nor discuss end-of-life issues

One participant declined to be provided with more information about her diagnosis. Once she was told that her cancer had spread, she was not interested in further discussions about her illness.

'I was told that the cancer has spread and they could not operate on me so let it be like that and I have accepted it there is no need for that…. I feel if the cancer has spread let it be and I accept it.' (P009)

Participant number nine refused to discuss end-of-life care issues. She withdrew from the study at question number six. After being asked question number six, there was silence for more than one minute. Her facial expression changed and she looked tense. She was offered a chance to see a counsellor but she refused. She never cried. The researcher counselled the patient. She was given an opportunity to come back at her own convenient time to continue the interview but she never came back.

'I am not interested to talk about that topic.' (P009)

6.3 Willingness to discuss end-of-life care issues

Most participants expressed the wish to discuss end-of-life care preferences.

'You should really understand because issues of death of person sometimes people don't like talking about them and to them it's a very difficult topic but we all know that we will die…..If you are prepared to talk about that then you make future plans and have a good life.' (P002)

'I will be interested to talk about this topic because I will know when I can get prepared and talk to my relatives about it so that they should also be prepared.' (P003)

'It is good to discuss this topic because I can make future plans with my family especially my wife.' (P007)

'I know this will lead me to death even if I fear death, the fact is that everyone will die even someone who is not suffering from cancer.....what is expected is for me to grab anything which comes on my way in form of assistance or advice even if they can tell me that I will die tomorrow…..' (P013)

Theme 7. Decision-making

7.1 Willingness to be involved

Some participants expressed the wish to be involved in decision-making about available care options.

'I was involved in making decisions of the type of treatment I wanted to take.' (P001)

'I would have loved if it was like that but for the time being they haven't involved me in any decision making about my treatment. They just offer us what is available, we don't choose…' (P002)

'I should say truly that I was not involved in decision for my treatment. I can be very interested being involved in making decisions of my life. When am I have been diagnosed with anything I like asking questions about it, for example why and how did this happen? But they don't involve us in decision making…..' (P003)

Study participant number 11 refused to be operated on because it was a major operation and the cancer had spread.

'I shouldn't lie, I refused to have an operation. He said he will put a tube on my abdomen so that my stools can come out through that tube since the growth in my rectum was blocking my stools. I said that is a major operation according to my age I can't manage……..' (P011)

7.2 Unwillingness to be involved

Participant number nine expressed the choice of not being involved in decision-making about available care options.

'……if there is any help they should just give me the medication……' (P009)

Theme 8. Place of care

8.1 Hospital care

Most participants chose hospital as a preferred place of care. Eleven study patients mentioned that hospital was their preferred place of care.

'What I want my guardian to do is to take me to the hospital because my wife will explain to the doctors what I am suffering from. Besides that, at the hospital, I will be assisted and treated properly.' (P001)

'To me I would rather be at the hospital if I became very ill. The doctors can try their best to assist me may be they will have other plans for me to get better but at home it will be difficult for doctors to see and treat me.' (P002)

'I want them to bring me to the hospital.' (P003)

'They should take me to the hospital where the doctors know my problem and they will know what to do to me so that maybe I can be saved from dying but if they will delay taking me to the hospital at that time I will be dead.' (P007)

8.2 Home care

Few participants chose home as a preferred place of care.

To be treated at home would be better because I am talking about transport costs, when I will be very sick I will not walk or move on my own. If I can be assisted at home, the doctor can come and help me at home and see what is needed and then came back with some necessities without troubling people to pick you with a car which is also expensive. Of course when you are treated at the hospital there are more advantages. As I am sick now, it is my wife who does most of the things at home including caring for the children. She is not employed and I am the bread winner of the house. It will be very difficult for my wife to leave home and be my guardian at the hospital because everything can at a standstill at home.' (P005)

'For me, I would prefer to be cared at home.' (P011)

Theme 9. Place of death

9.1 Hospital death

Most participants chose hospital as a preferred place of death.

'They should bring me to the hospital so that Doctors should try their part and see where they have failed. It could be that I might die during sleeping or I might just feel a headache it could happen that way but because when are you at home guardians stop doing their daily jobs because they are busy caring for you, so I would really want them to take me to the hospital.' (P001)

'If I will be very ill, the guardians should try their best to help me in any way they should not leave me alone to die, they should take me to the hospital immediately so that I should be assisted.' (P002)

'At the hospital there is peace. Doctors and nurses will be busy looking after you. Besides that, at the hospital, I will have faith that I will be assisted accordingly but if time will come for me to die then its Gods plan I will die.' (P006)

9.2 Home death

Of all the participants, only two participant chose home as a preferred place of death. Unfortunately her wishes were not implemented and she had several admissions to the hospital during her last days of life. She died in the hospital, contrary to her wishes.

You might find sometimes it difficult to breathe. This is a stage where you are gasping for air. When you reach that stage, you fail to breathe properly and there is need for oxygen which is not available at home and then your guardians become nervous and the guardians can make their own decision contrary to your preference and they end up taking you to the hospital, but if I will be very sick I should be cared at home.' (P011)

9.3 Difficulties in expressing the preferred place of death

One participant expressed difficulty in predicting the actual place of death.

'……it might be not the time for me to die because I don't know where and when I am going to die.' (P004)

Theme 10. Spiritual concerns

10.1 Prayer and faith

Some participants expressed the importance of prayer and faith in dealing or coping with incurable diseases.

'Because I know that God can make a way where there is no way that is why he has given wisdom and empowered these doctors to diagnose this cancer and helping them find medication that it is not our will but it is God's will. That is why I pray to him so that he should continue helping us in other ways through these doctors.' (P003)

'God is the one who keeps our lives and he can make anything impossible to be possible, I can make my plans but God has his own plans for me; it might be not the time for me to die because I don't know where and when am going to die.' (P004)

'The most important thing for them to remember is informing my church elders about my illness… what I want is that I should die in the name of Jesus so that when I die Jesus should be with me.' (P005)

10.2 Religious rituals

One participant expressed the wish of fulfilling religious rituals before the occurrence of death.

'I do envy those patients whom when they are about to die, they have talked to the priest or pastor and receive a sacrament of confession so that they should go to heaven and be with the Lord on his throne and I really wish if I could have that chance.' (P013)

10.3 Traditional healers

Some participants shared their individual opinions in relation to seeking help from traditional healers.

'I can do whatever the doctor will tells me but I do not believe in traditional healers.' (P005)

'The result is that the disease worsens when we are getting help from traditional healers. We present to the hospital when the disease has advanced and it is too late for the doctors to

help…. you can judge for yourself that this friend has been having this problem for a long time but they did not want to come to the hospital thinking that someone has bewitched him.' (P010)

5.0 Chapter Five: Discussion

5.1 Introduction

This chapter will interpret results of this researcher's study and integrate them with current knowledge. Most participants expressed their preferred place of care and death. The results of the researcher's study provides strong evidence that most participants were willing to discuss end-of-life care issues and that discussing death is not taboo in Malawi. Most participants wanted to know more about their illnesses so that they could make realistic future plans. Most participants were affected holistically by their incurable illnesses.

5.2 Awareness of reason for being at Tiyanjane Clinic for palliative care

During the interviews, the researcher did not explore the broader understanding of what palliative care meant to participants. What the researcher explored was whether participants had knowledge or not of the services that were offered by Tiyanjane Clinic.

All participants were aware of why they were receiving care at Tiyanjane Clinic. Most participants were aware of having an incurable illness. In this researcher's study, the participants acknowledged having received a holistic assessment of their physical, psychological, social and spiritual needs. Care options that participants received from Tiyanjane Clinic were: Pain relief with analgesics, including morphine and vincristine chemotherapy; counselling about disease understanding for the patients and their guardians; social care; and spiritual care.

Pain relief and effective treatment

Most participants in this researcher's study reported pain relief and receipt of effective treatment in the form of vincristine therapy. Findings in this researcher's study correspond with findings by Bates et al in 2013 at QECH, Blantyre, Malawi [60]. Bates et al reported that a number of patients interviewed had complained about uncontrolled pain before being referred to Tiyanjane Clinic, but the pain was controlled after patients had started receiving care from the Clinic [60]. In addition, in this researcher's study, participants' symptoms improved after they had

starting getting care from Tiyanjane Clinic. For example, for those participants with swollen legs due to cancer, the swelling disappeared after they had starting receiving vincristine.

Availability of drugs

In this researcher's study, a number of participants reported that essential palliative care drugs, for example vincristine, were out of stock in the government pharmacy and the participants had been advised to buy vincristine from private pharmacies.

The findings in this researcher's study correspond with findings by Bates et al in 2013 at QECH, Blantyre, Malawi, in an exploratory qualitative study of patients living with end-stage kidney disease not treated with renal replacement therapy [60]. Bates et al reported that the prescribed medications were not available in the government pharmacy, patients were being told to buy from other pharmacies and some patients went home without medication if they had no money [60].

Medical resources

Some of the medical resources that QECH lack are radiotherapy and reagents for biopsy samples. In this researcher's study, one participant voiced concern about the lack of medical resources in Malawi. This participant did not have money, but her children had paid for her care in India, where she was treated with radiotherapy. This participant further pointed out that most patients could not afford to go outside Malawi for treatment because of their poor socio-economic status. After the interview, the same participant voiced her relief about having had an opportunity to advocate for the ill and poor in Malawi.

The findings in this researcher's study correspond with findings by Gysels et al in 2011, in a systematic review of qualitative literature about end-of life-care in sub-Saharan Africa [19]. Gysels et al argued that care provision at the end of life is scarce across Africa because of a lack of resources and infrastructure [19].

Reflection

Tiyanjane Clinic provides total care of the whole person, as reported by participants. The participant who had voiced concern about a lack of medical resources had pointed out that patients could not access oxygen therapy at their homes in Malawi. The participant went on to say that, when the patient was gasping for air, the guardians ended up taking the patient to the hospital. The participant's wishes never materialized at the end of her life as the participant died in hospital, despite having voiced her wish to die at home. Had there been oxygen therapy at this participant's home, she would probably have died at home according to her wishes.

In addition, it is not known whether a lack of medical resources in Malawi means that patients who could be receiving curative treatment end up being offered palliative care.

5.3 Reluctance to discuss HIV

Most participants in this researcher's study found it easy to discuss care of cancer, but not care of HIV. For example, only two participants mentioned their HIV status and HIV care at the very beginning of the interviews. The findings in this researcher's study correspond with findings by Bohle et al in a 2014 cross-sectional pilot study on HIV status disclosure in the context of free antiretroviral therapy. In Bohle et al study was done at the Bombo regional hospital in the city of Tanga, Tanzania and it reported on the experiences of women living with HIV. [64]. Bohle et al concluded that disclosure of the HIV status remained a highly distressing thing for women because of a fear of discrimination [64].

One participant in this researcher's study had pointed out that some patients feel shy to discuss HIV because of the way that HIV is mostly transmitted.

Reflection

This reluctance to discuss HIV shows that HIV is still a stigma in Malawi. The researcher thinks that most participants were reluctant to discuss HIV because HIV infection is associated with promiscuity.

5.4 Psychosocial concerns

Emotional concerns

The findings by Gysels et al in 2011, in a systematic review of the qualitative literature about end-of-life care in sub-Saharan Africa, were supported in the case of most participants in this researcher's study [19]. Gysels et al stated that end-of-life care had been reported in most articles included in the authors' systemic review to be a psychological burden for carers [19]. In addition, Bates et al in 2013 stated that patients with end-stage kidney disease at QECH, Blantyre, Malawi, had experienced a psychological impact of the illness [60].

Most participants in this researcher's study reported having been worried when they were told about the diagnosis of incurable illness for the first time. However, acceptance helped most participants in this researcher's study to cope with the diagnosis of an incurable illness after being counselled by their palliative care team.

Social concerns

Some participants in this researcher's study felt that they were a burden to others, and they were therefore reluctant to ask for assistance. The researcher's findings correspond with what Singh et al reported from five hospices in Kwa-Zulu Natal, South Africa, in a study between December 2005 and March 2006 concerning stigma, burden, social support and willingness to care among caregivers of people living with HIV and AIDS in home-based care programmes [65]. Singh et al stated that caregivers who were not supported by volunteers and community nurses experienced high levels of burden of care [65]. One participant in this researcher's study was concerned that, at times, guardians can lock up the patient in the house and leave the patient alone when they are busy with other things, such as gardening. The participant further explained that, once the patient is alone, this affects the whole care of the patient in the sense that the patient will need to take medication and food at some point, as well as have a bath. This is most worrisome, especially in the case of bed-ridden patients.

Financial concerns

The study findings by Bates et al in 2013 at QECH, Blantyre, Malawi, were supported by most participants in this researcher's study, who were concerned about the financial constraints that the incurable illness had caused [60]. Bates et al reported that patients with end-stage kidney disease had mentioned many ways in which end-stage kidney disease had brought about financial constraints, which in turn had affected their care[60]. In addition, Gysels et al stated in a systemic review about end-of-life care in Sub-Saharan Africa that end-of-life care had been reported to be a financial burden for carers [19].

Most participants in this researcher's study were concerned about transport money to and from hospital, school fees, money to buy medications from private pharmacies and food for their families.

Loss of independence

Some participants in this researcher's study experienced a loss of independence as a result of their suffering from an incurable illness. Most participants were breadwinners in their families. However, due to their incurable illness, most participants had started depending on their families and other relatives for support. This resulted in loneliness and isolation of the participants when the guardians were busy with other things at home. The researcher's findings correspond with what Bates et al reported in 2013 at QECH, Blantyre, Malawi [60]. Bates et al reported that patients had experienced a reversal of roles in the family as a result of their having end-stage kidney disease, because their children now cared for them [60].

Overall, participants in this researcher's study were mostly dependent on the family members as a result of their having an incurable illness.

Reflections

Most participants spoke of the psychosocial impact of their diagnosis. The psychosocial concerns refer to "total pain" in palliative care. A holistic assessment should be done on every patient in order not to miss other causes of pain apart from physical causes.

5.5 Expressed emotions

The study findings by Bates et al in an exploratory qualitative study in Blantyre, Malawi, of patients living with end-stage kidney disease not treated with renal replacement therapy in 2013 were supported in the case of two participants in this study [60]. The two participants in this study cried during the interview. Bates et al stated that end-stage kidney disease patients were depressed after being told about the diagnosis and two patients had also cried after being told about the diagnosis of end-stage kidney disease [60].

Emotional responses were something this researcher had anticipated because of the sensitivity of the topic. Also, being in a position of facing imminent death evokes immense grief associated with multiple losses an individual has endured over time and the anticipated grief of the final loss, death, which is the termination and closure of one's life.

This was done by observing the behaviour of the participants and by taking some notes. This was explained to all participants before the interviews were started. Therefore, the researcher was prepared for such emotional responses, as was the case with one participant, when he paused the interview and asked the participant if she wanted to continue and offered tissues, which were accessible in the interview room. Two counsellors from Tiyanjane Clinic were available and assigned to offer emotional support to the participants, should they desired this.

Reflection

Sensitivity about this topic globally highlights the importance of creating safe spaces for individuals to talk about challenging issues concerning their illness. The researcher initially was ambivalent about conducting this researcher's study as the topic is labelled 'taboo'. In retrospect, it has been shown that initiating difficult conversations that address sensitive topics relieve individuals to a certain degree of the emotional burden, if conducted skillfully and sensitively.

5.6 Legacy

Most participants in this researcher's study expressed a wish to have their hopes for the well-being of their loved ones in place before they died. Such hopes were, for example, that the

children would get an education, that the family would have a house and that all concerns would be addressed in a will or another legal and binding document.

Meridian Life Design Inc. in 2009 defined legacy as a gift that is handed down or conveyed from one person to another or something that is left after a person has passed on; furthermore, legacy is when a person is genuinely grounded in offering his-/herself and making a meaningful, lasting and energizing contribution to humanity [72].

Most participants highlighted that the advantage of being cared for at Tiyanjane was that their problems were being holistically assessed and managed well. This resulted in participants' accepting their illness and being able to engage in making realistic future plans. From participants' responses it was evident that most of them wanted to leave a legacy for their children that would ensure that they would be remembered with dignity even after their passing.

Chochinov et al conducted a randomized controlled trial between 2005 and 2008 of 326 participants on the effect of dignity therapy on distress and end-of-life experience of terminally ill patients [73]. The authors concluded that most of the patients had found dignity therapy helpful because it lessened physical, psychosocial and spiritual distress for patients approaching death. One participant in this particular study had died without pain because she was on morphine and that was a dignified death.

All participants who spoke about leaving a legacy for their families were aware of their impending death and, even though this was not a welcomed event or thought, they displayed more discomfort and distressing symptoms about the uncertainty relating to what would happen to their families after their death if issues of concern were not discussed while they were still alive.

Reflection

The researcher thinks that participants wish to ensure that what they leave behind after their death will preserve a legacy that will bring comforting memories to their loved ones. In

addition, the researcher thinks that if a patient dies without pain or other distressing symptoms, the death is taken as a dignified death.

5.7 Receiving of information

The findings by Selman et al in a multi-centre, qualitative study conducted in South Africa and Uganda in 2009 were supported in this researcher's study, since 12 participants in the researcher's study wanted to have more information about their illnesses [63]. Selman et al reported that patients and caregivers wanted more information about the causes and progression of the illness [63]. Similar findings were also reported in some studies conducted by Harding et al in 2013, Zafar et al in Pakistan in 2016, Heckel et al in Germany in 2016, and Fourie, who reported from Pretoria in South Africa in 2008 that adult cancer patients and family caregivers wanted an honest disclosure of their disease prognosis [28, 32, 34, 66].

Advance directives

This is a new sub-theme that emerged from this researcher's study and which the researcher had not anticipated. In this researcher's study, two participants voiced their concern about future planning after being told about their terminal diagnosis. The researcher believes planning ahead can help participants think about the goals of each care option and help them weigh the benefits and burdens of each care option. For example, what are the benefits of going to India from Malawi for treatment when the disease has already spread to different organs, when a curative option is no longer possible and when all the money has been spent and children are left with no school fees? Patients need to be given true and honest information in order to make realistic plans. In this researcher's study, one participant had gone to India for treatment and died a few months later.

Also, in this researcher's study, one participant's wishes were unfortunately not implemented, because her wishes had not been documented. The participant died in hospital, yet her wish had been to die at home. The researcher feels that patients' wishes should be communicated to and discussed with family members and should later be documented before a health crisis occurs, when the patient may no longer be able to make a decision.

In this researcher's study, most participants were willing to discuss end-of-life care issues; therefore it is the duty of all healthcare workers to start advanced care planning discussions with their patients.

The future planning concerns in this researcher's study were also raised in a 2013 study by Stanford et al about conversations worth having and entitled "The perceived advanced care planning among teachers, hospice staff and pastors in Knysna, South Africa." ; the authors stated at the time that advanced care planning should take place before a health crisis. [70].

Communication skills

The findings by Bates et al in 2011 in Malawi were supported by one participant in this researcher's study who did not want to be given more information about the incurable illness[5]. The study participant in this researcher's study decided to withdraw and did not return to continue the interview.

Bates *et al* stated that professionals should find out how much information the patient has in the "breaking bad news protocol" known as ASK-ASK-TELL-ASK-ASK-PLAN.

In addition, the 2012 findings by Downing et al in Nairobi, Kenya, were further supported by the fact that one participant in this researcher's study refused to receive more information once she had been told that she had cancer [40]. Downing et al similarly reported that one study participant was upset about talking about the topic and refused to be told about a terminal diagnosis in a pilot street survey [40].

In this research study, interviews coincided with Christmas and New Year. Discussing end of life care choices during festive session could have been even more sensitive for the participants as the interview could have highlighted isolation from family caused by the illness and also evoked a sense of loneliness and missing home particularly during the festive season. The researcher was mindful of such emotional responses and anticipated them hence a psychosocial counselling team was available and ready to offer support should there be any identified or reported distress experience.

On the contrary, most participants in this researcher's study still wanted to be given more information about their illnesses, even if the news was bad.

Reflection

Twelve participants wanted to be given more information about their incurable illnesses. This indicates that the need for information is a crucial factor among palliative care patients in Malawi.

As mentioned, patients' wishes were not always implemented. In this researcher's study one participant's wishes were unfortunately not implemented. This brings into question whether more emphasis should be given to advance care planning and communication skills in palliative care provision in Malawi.

As evidenced by the participant who did not want to receive more information about the incurable illness, some patients do not want to know more information about the illness when the expected news is bad. In situations like this the researcher feels that the patient's autonomy and choice need to be upheld and respected.

5.8 Decision-making

Both European and African studies have shown that patients want to be involved in decision-making about their care [32, 40].The findings by Downing et al in Nairobi, Kenya, in a survey about public preferences for end-of-life care, and Harding et al in 2013, in a public survey of preferences relating to disclosure of poor prognosis that was done in England, Belgium, Germany, Italy, Netherlands, Portugal and Spain, were supported in the case of most participants in this researcher's study [32, 40]. Harding et al reported that 74% of the participants wanted to be involved in decision-making when capable [32]. Similarly, in a Kenyan study done in 2014, the majority of participants wanted to be involved in decision-making [40].

However, a few participants in this researcher's study felt that choices about being involved were less important, because they believed that doctors had the best interest of patients at heart, so participants were therefore only looking for help.

Reflection

The learning point was that participants in this researcher's study who had significant trust in doctors did not mind whether they were involved or not in decision-making. However, the researcher believes that, once patients are involved in decision-making, they have an idea of what to expect in terms of the goal of care, which is planned together with the patient. Also, the researcher believes that planning together with patients can help avoid situations where patients regret having started a care option that is futile.

5.9 Place of care

Hospital care

Eleven participants mentioned that hospital was their preferred place of care, despite their having had a terminal diagnosis. The main reason for choosing hospital was that patients were looking for professional help that would benefit both themselves and their caregivers. Participants stated that hospital care offered patients assurance of professional availability and medical assistance when required, while, on the other hand, for caregivers, hospital care offered relief from daily nursing care of the patient and time for them to mind other business. These participants' responses corresponded with arguments by Jang and Lazenbay, who wrote in 2013 that, in Africa, analgesics were best accessed at inpatient level, hence pain and end-of-life care symptoms were best managed at inpatient level [67].

The other factor that influenced participants' choice of hospital care was burden of care on caregivers. One participant in the researcher's study mentioned that, at home, family members would lock the patient up in the house and leave him or her alone because they were busy with other things, like gardening. Another participant voiced concern that, when one is sick at home, caregivers and guardians stop doing their daily jobs because they are caring for the sick relative. All participants who preferred hospital care reported that, at home, patients might be left to suffer due to the increasing burden of care on caregivers and family.

The researcher's findings correspond with findings by Gysels et al in 2011, in a systematic review of qualitative literature on end-of-life care in sub-Saharan Africa, in which they

concluded that patients and carers preferred institutional care [19]. In addition, Uwimmama, in a study conducted in Rwanda in 2008, also found that the hospital was the most preferred place of care in Rwanda. The main factor that might have influenced the choice of hospital care in Rwanda could have been that the study was done after civil war and genocide, which is not the case in Malawi [48].

In a study conducted by Ndata-Mbata and Seloilwe in Botswana in 2000, it was found that, despite having well-structured home-based palliative care programmes in place, most palliative care patients had an increased rate of readmission to hospital at the end of life [61]. It is not known whether home-based care services in Malawi are capable of providing palliative care adequately enough to result in a reduced burden of care for caregivers and whether it will provide assurance for effective symptom management at home that would reduce hospital readmission at the end-of-life stage.

Home care

In this researcher's study, only two participants out of 13 chose home as the preferred place of care. The reasons for choosing home care were that it is less costly for the patient and the family, there is no wastage of money for travelling, it allows networking between the healthcare facility and the community through home visits, and guardians have time to do household chores. The selection of home as the preferred place of care by two of the participants is supported by Merriman in a study conducted in Uganda in 2006 in which it was highlighted that home was the most preferred place of care at the end of life [44].

What came as a surprise in this researcher's study is that an overwhelming majority of participants did not select home as their preferred place of care at the end of life, a response which is at odds with most literature. In a study conducted by Tapfield and Bates in 2011 at Tiyanjane, the same palliative care clinic in Malawi where the researcher's study was conducted, the authors reported that 65% of 177 patients had been discharged to go home by Tiyanjane Clinic between the months of April to September 2009 [42].

In a survey conducted by Loh et al in Singapore, 2016, findings were that home care was the most favoured choice and quality of care at home was rated as 'good' or 'excellent' by patients and their family members. These findings were supported by one participant in this researcher's study who stated that the advantage of home care was that patients had the full support of family members.

The argument by Merriman in Uganda in 2006 was further supported in that two participants in this researcher's study highlighted that home was the most preferred place of care at the end of life [44].

Reflection

The researcher finds it hard to believe that only two participants chose home as their preferred place of care. The study findings are at odds with what Tapfield and Bates reported in 2011 at Tiyanjane Clinic, Blantyre, Malawi 42. In 2011, Tapfield and Bates reported that 65% of 177 patients had been discharged to go home by Tiyanjane Clinic between the months of April and September 2009 42. The researcher wonders whether home-based services were better then than they are now.

It may be better to have an evaluation of the current status of and resources for home-based palliative care programmes and compare that with the findings from the Tapfield and Bates study that was conducted in 2011.

In addition, the researcher thinks that hospital may not be the ideal place of care because the patients become a burden to the hospital in terms of food, water, electricity and beds. For example, QECH offers free services, which sometimes become difficult to sustain. To be at the hospital is also a burden to the guardians as they have to prepare decent meals and spend money on transport to and from the hospital every day.

Palliative care patients should be advised to have advanced care directives. Advanced care directives could guide family members about end-of-life care plans for the patients. In this

researcher's study, the wishes of the participant who was taken to hospital by the guardians contrary to her choice had not been documented.

5.10 Place of death

In this researcher's study, 11 participants out of 13 chose hospital as the most preferred place of death, despite having had a diagnosis of an incurable illness. The reason for choosing a hospital death was that the 11 participants wanted to access professional care from doctors and nurses despite their having a terminal diagnosis. In addition, the participants expressed fear that they might die earlier at home before the actual time of death, if not taken to hospital. The researcher thinks that participants were afraid to die at home because other causes of death could be reversible, despite their having a terminal diagnosis. For example, a patient with lung cancer could die earlier from severe bacterial pneumonia rather than from the lung cancer itself if the severe bacteria pneumonia is left untreated. Also, patients with a terminal diagnosis may suffer from superimposed infections which, if treated, may prevent an earlier death.

The choice of a hospital death by 11 participants in this researcher's study came as a surprise because it is at odds with most literature. Kikule in Kampala, Uganda, in 2000, Merriman in Kampala, Uganda, in 2006, and Downing et al in Nairobi, Kenya, in 2012, all reported that home was the most preferred place of death [3, 40, 44].

However, the 11 participants in this researcher's study supported the findings by Gomes and Higginson, who argued in 2004 that home deaths in patients with cancer in the United Kingdom had dropped from 27% in 1994 to 22% in 2001. In 2008, Gomes and Higginson further suggested that home deaths would be dropping until 2030 [51, 62]. The researcher believes that it is not only the question of resources that influence the preferred place of death, because patients in the West have many options to choose from – for example, hospices, nursing homes and inpatient palliative care units where patients can choose to die, unlike in Malawi where the options are limited because patients have to choose between home and hospital.

The researcher finds it hard to believe that only two participant out of 13 participants in the researcher's study chose home as a preferred place of death. The main reason could have been that the participants had a full family support system at home. In addition, one participant out of the two in the researcher's study who chose home as the preferred place of death was on a medical aid scheme; as a result the participant could access appropriate drugs at home from private hospitals and pharmacies, unlike the other participants.

Unfortunately, the wishes of one participant in this researcher's study were not implemented by the family members because the participant died in the hospital against her wish. The main reasons that could have influenced the guardian to take this patient to the hospital are: Lack of experience of death by family members; it could be embarrassing to see a family member dying at home (culturally, if one dies at home in Malawi, the family is blamed for not having done enough by not taking the sick person to the hospital); and avoidance by healthcare workers to start death conversations before the crisis happens. The finding in this researcher's study is at odds with most African literature, because Kikule, Merriman and Downing et al argued that home is the most preferred place of death in most African countries [3, 40, 44].

Two participants declined to express their preferred place of death. Participants stated that it was difficult to predict the actual time when and where death would occur. The researcher believes that, once a patient has been diagnosed with a terminal illness, it does not mean that the patient is going to die soon. The researcher has seen patients with terminal illnesses at Tiyanjane Clinic staying for many years before the end-of-life care crisis. Then it becomes difficult to predict the time and place where death is going to occur. The researcher's findings correspond with what Kiely et al reported in Sydney, Australia, in 2010 [38]. The authors concluded that death is uncertain and unpredictable with or without cancer and it is sometimes difficult to predict the survival duration [38].

Reflection

The researcher found that it was easier for both the researcher and participants to discuss the preferred place of care as opposed to the preferred place of death with all participants. In

addition, the researcher's findings suggest that participants' choices were influenced mainly by a lack of resources in the community.

My supervisor's sense from going through the transcripts has been that, even though discussing death is a sensitive topic, it is not a taboo, as most participants engaged with the topic. Most participants expressed appreciation for having a safe space created for them to talk about this sensitive topic.

5.11 Spiritual concerns

Bauer defined spirituality as a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose and transcendence and experience relationship to self, family, others, community, society, nature and the significant or sacred [71]. Bauer further explained that spirituality is expressed through beliefs, values, traditions and practices [71]."

Most participants expressed spiritual concerns. Spirituality generally helped the participants deal with their incurable illnesses. The findings in this researcher's study correspond with what Bates et al reported in 2013, in an exploratory qualitative study done in Blantyre, Malawi, about patients living with end-stage kidney disease not treated with renal replacement therapy [60]. Bates et al reported that spiritual belief had a role in patients' acceptance of end-stage kidney disease at QECH [60].

In addition, Sankhe et al concluded in India in 2014, in a prospective, non-randomized, single-cohort study about spiritual care therapy on quality of life in cancer patients and their caregivers, that spiritual care increased both the spiritual and general well-being of both cancer patients and their caregivers [21].

However, the views of two participants in this researcher' study supported what Bates et al had reported in 2013 in Blantyre, Malawi, where a participant in abovementioned study believed according to local cultural belief that the cause of end-stage kidney disease was witchcraft [60]. The cultural belief in abovementioned study corresponds with what two participants in the researcher's study emphasized that some patients presented late to hospital, when the disease had advanced, because they had first sought help from traditional healers.

Reflection

The researcher thinks that participants wish to ensure that what they leave behind after their death will preserve a legacy that will bring comforting memories to their loved ones. In addition, the researcher thinks that if a patient dies without pain or other distressing symptoms, the death is taken as a dignified death.

5.12 Reflexitivity

The researcher could have influenced the research, in the sense that the researcher works in the same department as a senior palliative care clinician and with the same patients that were interviewed in this researcher's study. This might have put pressure on the participants not to be fully free to air all their views. It is not known whether an independent interviewer who does not work in the palliative clinic could have generated the same research findings. However, the personality of the researcher is such that he is liked by many patients in the Clinic because he presents an unconditional, positive regard for every patient during consultations, an attitude that may have made participants feel more comfortable during the interviews, in the process influencing the research results.

Summary

This researcher's study has brought new knowledge in Malawi and possibly other countries in Africa. Previously discussing death in Malawi was taken as a taboo. However the majority of the participants in this researcher's study were free and eager to discuss end of life care issues. The participants in this researcher's study appreciated end of life care discussions because the discussions helped the participants to have realistic future plans. In addition, community services need to be evaluated because the community services influence patients' preferences and priorities for end of life care in Malawi.

5.13 Areas of further research

It may be important to conduct a study to explore whether advance directives or living wills should be offered as part of care for palliative patients in Malawi. Advance directives or living wills may help health workers and patients' families to respect patients' choices.

It may also be important to conduct a study to explore current status of home based palliative care services in Malawi because most participants chose hospital as a preferred place of care because of lack of resources in the community.

It may also be important to look at confidence or skills of palliative care providers to discuss preferences and priorities for end of life care in Malawi.

5.14 Study limitations

The research findings cannot be generalized in Malawi but, for the findings to be generalized, a large quantitative study should be done involving different palliative care sites in Malawi.

During the research, the researcher discovered that he lacked probing skills in some areas where participants could have been assisted to open up about areas that were of concern to them. For example, mention of the use of traditional healers had come from two participants, but the researcher did not probe more to uncover participants' views or concerns regarding the use of traditional healers.

This researcher's study was conducted on Wednesdays and Thursdays, which were general cancer and KS clinic days respectively; therefore the researcher might have missed the preferences and priorities of patients with other conditions.

5.15 Study strengths

The research findings have highlighted that talking about death in Malawi is not completely a taboo as previously suggested because most participants were very willing to discuss about end of life care preferences and priorities.

The research findings have contributed to evidence based palliative care practice at Tiyanjane clinic because there is little or no evidence based literature about patients' preferences and priorities for end of life care in Malawi.

Chapter Six: Conclusion and Recommendations

6.1 Conclusion

This study aimed to explore preferences and priorities for end of life care experienced by adult patients with a terminal diagnosis. It is important to explore current knowledge, thoughts and gaps in end of life care for patients with terminal diagnosis as this helps health workers, the patients and their families to make future and realistic plans about the kind of care patients will receive at the end of their lives.

It is crucial for health workers to assess how much information patients would like to be given about their illness. For example, in the event whereby a patient refuses to receive more information about their illness, but the health worker proceeds to share the information, such action may cause more harm than good to the patient. This would be unethical conduct by the health worker and would be violating the patient's right to refusal of treatment/information.

Patients originate from diverse cultural and spiritual backgrounds and these affiliations hugely impact their decision-making processes. Health workers need to assess patients' preferences and choices in terms of their being or not being involved and/or who should or should not be involved in healthcare decisions. The advantage of conducting accurate assessment on the patient's preferred choices in terms of involvement in decision-making or lack thereof, is that there will be consensus between the patient, family and health workers on who should be involved in discussions and decisions taken on goals of treatment at the end of life. For those patients who would not like to be involved in health care decisions, their choice should be respected by health workers, other carers and their families.

Discussing end of life care in Malawi was regarded as a taboo. However, the researcher's study has shown that majority of the participants except a few, were very willing to discuss end of life care issues. Furthermore, studies to investigate whether patients with a terminal diagnosis have a preferred place of death, need to be conducted. This can help health workers and patients' families to respect patients' preferences and priorities with regards to a preferred place of death rather than changing them.

6.2 Recommendations

It would be important to empower- health workers in all health facilities in Malawi with palliative education and training. The Ministry of Health could Offer and make palliative care training compulsory. Communication skills are a core component of palliative care training and many health workers lack communication skills. All health workers should often be reminded to always engage in ethical behaviour and to uphold human and patient rights. Empowering health workers in all health facilities with palliative care education and training could help patients to access palliative services even in hard to reach areas and rural communities of Malawi.

Having to travel long distances to access palliative care could act as a barrier for patients and families with palliative care needs. Palliative care education could be conducted in various health care centres whereby a health worker could be offered a five-day training course and clinical placement and mentorship for two weeks on how to provide palliative care. Such community based palliative care training would ensure that health workers who work in a specific community are encouraged to be familiar with cultural practices and spiritual rituals or observations of the people they serve. Such understanding of patients' context would strengthen health worker confidence in providing support and promoting patient autonomy and respect for their preferences and choices with regards to decision-making during end of life care.

There is increased need to have health promotion to empower patients and families on their rights to health care. The researcher suggests that the first step that should be taken is to create greater openness and patient empowerment in health care settings. This calls for adequate funding for health services so that more staff can be employed and trained to equip them appropriately with skills and sufficient time to deliver services.

Health workers, patients' families and other caregivers need to respect people's preferences and priorities for end of life care. Although choices are limited, patients with terminal illnesses do want to make choices about their place of care and place of death therefore health workers and family members should not change or disregard people's preferences and priorities for end of life care but rather respect and uphold them to the best of their ability.

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APPENDICES

Appendix 1. Letter requesting permission to conduct research at research site.

LETTER REQUESTING PERMISSION

Queen Elizabeth Central Hospital

P.O. Box 95

Blantyre, Malawi

Date……..

The Hospital Director

Queen Elizabeth Central Hospital

P.O. Box 95

Blantyre, Malawi

CC:

Medical Director, Palliative Care Support Trust Queen Elizabeth Central Hospital

Team Leader, Tiyanjane Palliative Care Clinic, Queen Elizabeth Central Hospital

Dear Sir/Madam,

I hereby ask permission to conduct a research study at Tiyanjane palliative care clinic. The title of the research study is: **An exploration of patients' preferences and priorities for the end of life**

care at Tiyanjane Palliative Care clinic, Queen Elizabeth Central Hospital, Blantyre, Malawi. This study is in partial fulfilment of my MPhil degree in Palliative Medicine.

The researcher will be recruiting adult palliative care patients who attend Tiyanjane palliative care clinic and are able to communicate fluently in English or Chichewa. Participants will have to give consent to participate. Those who are too sick, mentally or emotionally incapable to participate will be excluded from the study

Arrangements will be made with Tiyanjane clinic management to have designated Tiyanjane palliative care team members who will counsel and/or debrief patients in the event that a patient becomes distressed. A private interview room will be requested for conducting face to face semi structured interviews.

A research assistant will work closely with Tiyanjane clinic staff in identifying candidates who meet the inclusion criteria. The research assistant will approach and introduce the study to eligible participants. The research assistant will explain that the study encourages patients to talk about their concerns and wishes regarding ongoing provision of health care. Thereafter, individuals who are willing to hear more about the study will be identified. Willing participants will receive treatment first before being taken to the interview room within Tiyanjane palliative care clinic.

In the interview room the research assistant will provide further information using the information sheet and consent form. If the patient consents, the researcher will ask the patient to sign the consent form. Immediately thereafter, the researcher who is an experienced Tiyanjane clinic staff member will conduct semi structured face to face interviews. An audio tape recorder will be used to capture the interview.

All patients will have the opportunity to halt the interview at any time if they experience discomfort of any kind. Patients will be allowed freedom of choice to either terminate or restart the interview if they wish.

The research findings will be provided to Tiyanjane clinic and QECH medical department. The researcher is looking forward to working with you once full ethical approval has been received

from UCT Research Ethics Committee and permission granted by Malawi College of Medicine Ethics Committee. For any further information you may contact the researcher or research supervisors.

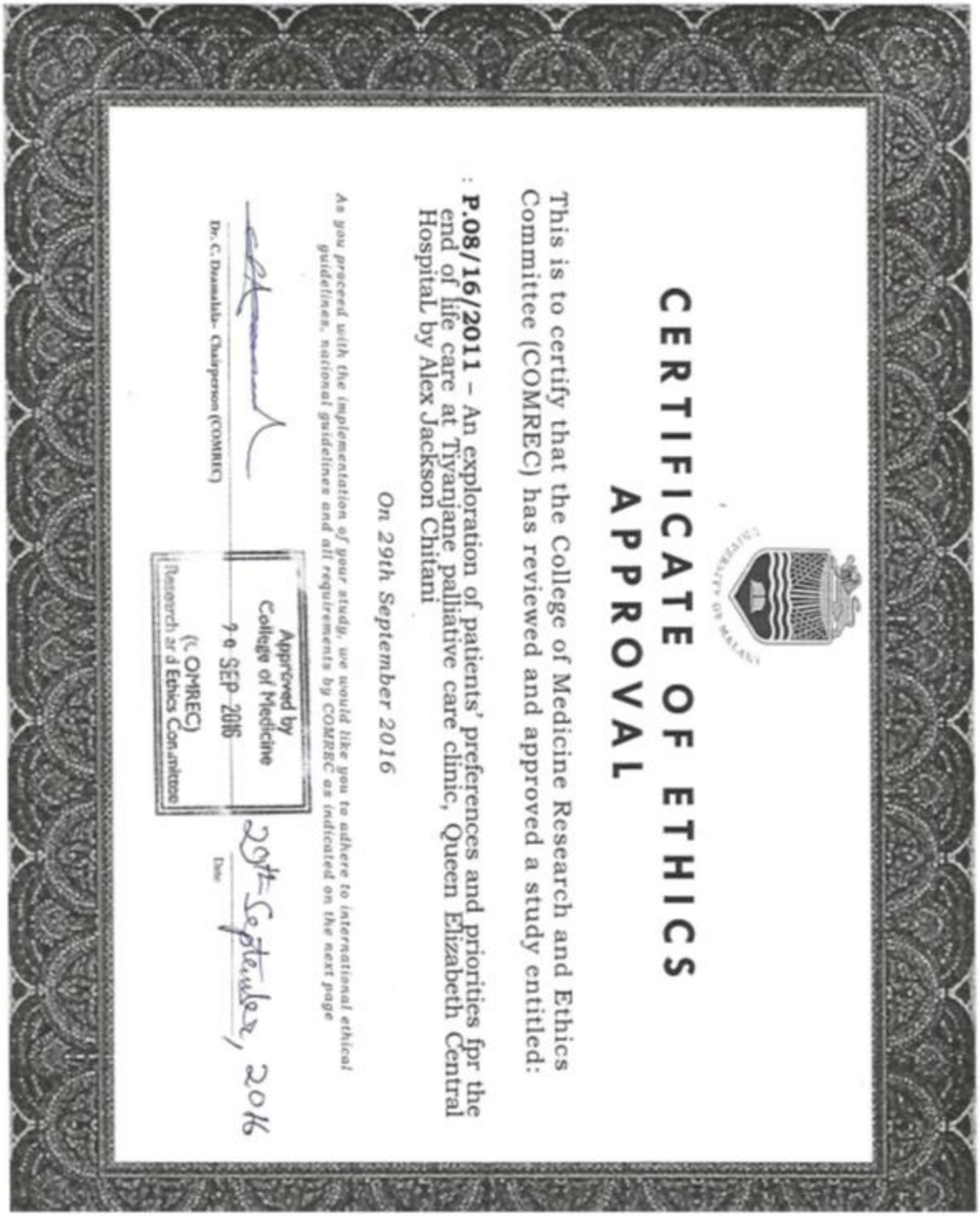
Yours sincerely

Alex Chitani (Researcher) - 0999 295 804 - alex.chitani2013@gmail.com

Supervisor: Mrs Linda Ganca 00 27 21 406 6590 linda.ganca@uct.ac.za

Co-supervisor: Dr Jane Bates - 0999 208 193/ 0882 002 193 - mjanebates@gmail.com

Appendix 2. Certificate of Ethics Approval (COMREC)



CERTIFICATE OF ETHICS APPROVAL

This is to certify that the College of Medicine Research and Ethics Committee (COMREC) has reviewed and approved a study entitled:

: **P.08/16/2011** – An exploration of patients' preferences and priorities fpr the end of life care at Tiyanjane palliative care clinic, Queen Elizabeth Central Hospital by Alex Jackson Chitani

On 29th September 2016

As you proceed with the implementation of your study, we would like you to adhere to international ethical guidelines, national guidelines and all requirements by COMREC as indicated on the next page

Dr. C. Dzamalala- Chairperson (COMREC)

Approved by College of Medicine 29 SEP 2016 (COMREC) Research and Ethics Committee

29th September, 2016

Date

.

Appendix 3. Letter granting permission to conduct a research at research site

Telephone: (265) 01 874 333 / 677 333
Facsimile: (265) 01 876928
Email: queenshosp@globemw.net

All communications should be addressed to:
The Hospital Director

In reply please quote **No.**

QUEEN ELIZABETH CENTRAL HOSPITAL
P.O. BOX 95
BLANTYRE
MALAWI

Ref No. QE/10 **25th July, 2016**

Alex Chitani
Queen Elizabeth Central Hospital
P. O. Box 95
BLANTYRE

Dear Alex,

PERMISSION TO CONDUCT A RESEARCH STUDY

This is to inform you that permission has been granted to conduct a research study entitled **"AN EXPLORATION OF PATIENTS' PREFERENCES AND PRIORITIES FOR THE END OF LIFE CARE"**, at Tiyanjane Pallistive Care Clinic, Queen Elizabeth Central Hospital.

We will appreciate if a copy of your findings is shared with the hospital.

All the best in your studies.

Yours faithfully,

L. Chewere
ACTING DEPUTY HOSPITAL DIRECTOR – NSG
For: HOSPITAL DIRECTOR

Appendix 4: HREC approval

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

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

03 November 2016

HREC REF: 614/2016

Ms L Ganca
School of Public Health & Family Medicine
Falmouth Building
FHS

Dear Ms Ganca

PROJECT TITLE: AN EXPLORATION OF PATIENT'S PREFERENCES AND PRIORITIES FOR END OF LIFE CARE AT TIYANJANE PALLIATIVE CARE CLINIC, QUEEN ELIZABETH CENTRAL HOSPITAL, BLANTYRE MALAWI (Master's candidate - Mr A Chitani)

Thank you for your response letter dated 24 October 2016, addressing the issues raised by the Human Research Ethics Committee (HREC).

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

Approval is granted for one year until the 30 November 2017.

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; A Chitani will also be involved in this study.

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

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

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637.

HREC 614/2016

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.

Appendix 5: Information sheet

AN EXPLORATION OF PATIENTS' PREFERENCES AND PRIORITIES FOR THE END OF LIFE CARE AT TIYANJANE PALLIATIVE CARE CLINIC, QUEEN ELIZABETH CENTRAL HOSPITAL, BLANTYRE, MALAWI.

Thank you for giving your time to hear about this study. This information sheet tells you about a study that you may wish to take part in. The information sheet is for you to keep. I will go through the information with you and if you may have questions to help you decide whether you want to take part, please ask them. I will be happy to answer them and explain the study further. Please note that participation in this study is voluntary, meaning that you are not forced to take part. Please take your time to make a decision.

What is the purpose of the study?

This study looks at patients' preferences and priorities for the end of life care at Tiyanjane palliative care clinic at Queen Elizabeth Central Hospital, Malawi.

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, your care 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.

What will happen if I take part?

A researcher who is also a staff member at this clinic will conduct the interview. The researcher will speak to you and ask you questions about your preferences and priorities for the end of life care. It will take about thirty to forty five minutes to conduct the face to face interview which will be audio recorded.

Benefits of the study

There are no direct benefits to the study for participants. The anticipated benefit is affording a disease understanding and safe space for the interviewee to share individual concerns pertaining preferences and priorities for end of life care and the possibility of improved palliative care services in light of this study's findings.

What are the risks of the study?

Answering some questions might cause an emotional response. There will be a designated team of palliative care counselors who will attend to patients' distress. In the event that there is emotional response, the researcher will stop the interview and appointed counselors will attend to emotional needs of the interviewee.

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 research a report will be sent to Tiyanjane palliative care clinic and to the participants who indicate that they would like to have the results.

Who is organizing the research?

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

Researcher*:* Alex Chitani Queen Elizabeth Central Hospital (QECH): 0999 295 804

Dr. Cornelius Huwa QECH: 0999 374 103

Supervisor: Mrs. Linda Ganca, University of Cape Town: 00 27 21 406 6590

Co-supervisor*:* Dr. Jane Bates, Malawi College of Medicine: 0999 208 193 /0882 002 193

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

COMREC Secretariat, Malawi College of Medicine. Phone number: 01 871 911

Appendix 5: UTHENGA WA KAFUKUFUKU (CHICHEWA VERSION)

KUFUFUZA ZA CHISAMALIRO NDI ZINTHU ZINA ZOFUNIKIRA ZIMENE ODWALA ANGAKONDE KULANDIRA KUMAPETO A MOYO WAWO PA TIYANJANE PALLIATIVE CARE CLINIC, QUEEN ELIZABETH CENTRAL HOSPITAL, BLANTYRE, MALAWI.

Zikomo kwambiri popelekeka nthawi yanu kuti munve za kafukufuku ameneyu. Chipepala cha uthengachi chikukulongosolerani za kafukufuku amene akuchitika ndipo mukafuna mukhonza kutenga nawo mbali. Chipepala cha uthengachi ndi chanu ndipo muyenera kuchisunga. Tiwerengera pamodzi zokhuza kafukufuku ameneyu ndi cholinga chakuti munvetsetse ndikufunsa mafunso musanapange chiganizo cholowa mu kafukufuku kapena ayi. Ine ndidzakhala osangalala kuyankha mafunso ndi kulongosola zambiri zokhuza kafukufuku ameneyu. Kumbukirani kuti kulowa mu kafukufuku ameneyu ndikufuna Kwa inu, kutanthauza kuti simuli okakamizidwa kulowa mu kafukufuku ameneyu. Ndikukupemphani kuti mukhale ndi nthawi yokwanira yoganiza musanapange chigamulo chanu cholowa mu kafukufuku ameneyu kapena ayi.

Kodi cholinga cha kafukufuku ameneyu ndi chiyani?

Kafukufuku ameneyu akufuna kumva maganizo a anthu odwala pa za chisamaliro ndi zithu zina zimene zingadzakhale zofunikira Kwa iwo kumapeto a moyo wawo pa Tiyanjane palliative care clinic Queen Elizabeth Central Hospital, Malawi.

Kodi ine ndine oyenera kulowa mu kafukufuku ameneyu?

Ayi, inu simuyenera kulowa mu kafukufuku ameneyu. Koma ngati mukuvomera kulowa mu kafukufuku ameneyu, muli ndi ufulu wotuluka mu kafukufukuyu nthawi ina ili yonse opanda kupeleka chifukwa. Kaya musankha kulowa mu kafukufuku kapena ayi, chisamaliro chimene mumalandila ku Tiyanjane SICHIDZASITHA chifukwa cha kuti mwalowa kafukufuku kapena ayi.

Ngati muli okonzeka kulowa mu kafukufuku ameneyu, mudzapemphedwa kusaina kapena kudinda chala pa pepala kusonyeza kuti mwavomera kulowa mukafukufuku ameneyu. Mutha kutenga nthawi yanu ndikuganiza mofatsa ngati mukafuna kulowa nawo mu kafukufukuyu. Mulinso ololedwa kukakambirana ndi aku banja lanu, amzanu kapena aliyense amene amakusamalirani zokhuza kafukufuku.

Kodi chidzachitike ndi chiyani ngati ine ndasankha kulowa mu kafukufuku ameneyu?

Wofufuza za kafukufuku ameneyu amenenso ndiwogwira ntchito pa chipatala pompano, adzakufunsani mafunso okhudzana ndi kafukufuku ameneyu. Cholinga ndikufuna kumva maganizo anu pa za chisamaliro ndi zinthu zimene zingadzakhale zofunikira kumapeto a moyo wanu. Kukambirana Kwa pamaso ndi pamaso kudzatenga nthawi pafupufupi mphindi makumi atatu ndi mphindi makumi anayi. Zokambiranazo zidzatepedwa ndikusungidwa mu makina osungira mawu.

Kodi ubwino wolowa mu kafukufuku ameneyu ndi wotani?

Phindu la pamaso ndi pamaso mukafukufuku ameneyu palibe. Ubwino ulipo ndiwakuti olowa mukafukufuku ameneyu adzakhala omasuka kukamba nkhawa zawo zonse pa zimene odwala angadzakonde kumapeto a moyo wawo. Malo a zokambirana adzakhala chipinda chopanda mphokoso ndi zosononeza. Ubwino wina ndiwakuti, zotsatira za kafukufuku ameneyu nkutheka kuti zizathandiza kupititsa chisamaliro cha odwala patsogolo kuno ku Tiyanjane.

Kodi kuipa wolowa mu kafukufuku ameneyu ndi kotani?

Kuyankha mafunso a mukafukufuku ameneyu akhonza kubweretsa nkhawa zina ndi zina chifukwa zokambirana zake ndizokhudza chisamaliro cha munthu kumapeto a moyo wake. A Tiyanjane a dzakhala okonzeka Kukambirana ndi munthu amene adzakhale ndi nkhawa zina ndi zina pa nthawi ya zokambirana. Wofufuza za kafukufuku ameneyu adzayimitsa zokambiranazo ndi cholinga chakuti munthuyo athandizidwe ndi a Tiyanjane.

Kodi ine ndikalowa mu kafukufuku ameneyu, zokambiranazo zisasungidwa mwa chinsinsi?

Zokambirana zonse zisasungidwa mwa chinsinsi kwambiri. Munthu aliyense sadzatchulidwa dzina ndi ngakhale kumene akuchokera. Maina anthu sadzaikidwa pamodzi ndi zimene adzidzakambirana. Munthu aliyense adzapatsidwa nambala yake ya kafukufuku. Aliyense amene sakupanga nawo kafukufuku ameneyu sadzakhala ndi mpata wopeza zokambiranazo chifukwa zidzasungidwa malo wobisika.

Kodi ine ndidzadziwa bwanji zotsatira za kafukufuku ameneyu?

Zotsatira za kafukufuku ameneyu zizapezeka ku Tiyanjane komanso zizatumizidwa kwa anthu wofuna kumva zotsatira, kwa okhawo amene adzalowe mu kafukufuku.

Kodi ndindani akuyang'anira kafukufuku ameneyu?

Ngati muli ndi mafunso ena okhudza za kafukufuku ameneyu, Mutha kufunsa anthu awa:

Wochita Kafukufuku: Alex Chitani Queen Elizabeth Central Hospital (QECH): 0999 295 804

Mkulu wa Palliative care pa QECH: Dr. Cornelius Huwa: 0999 374 103

Mkulu woyang'anira kafukufuku: Mrs. Linda Ganca, University of Cape Town: 00 27 21 406 6590

Wachiwiri kwa wa Mkulu woyang'anira kafukufuku: Dr. Jane Bates, QECH: 0999 208 193 /0882 002 193

Zokhuza za ufulu wanu wa umunthu mu kafukufuku, funsani ku UCT Research Ethics Committee*: COMREC Secretariat, Malawi College of Medicine Nambala ya foni: 01 871 911*

Appendix 6: Consent form

Title of research project: AN EXPLORATION OF PATIENTS' PREFERENCES AND PRIORITIES FOR THE END OF LIFE CARE AT TIYANJANE PALLIATIVE CARE CLINIC, QUEEN ELIZABETH CENTRAL HOSPITAL, BLANTYRE, MALAWI.

Names of principal researchers: Mr. Alex Chitani, Mrs. Linda Ganca and Dr. Jane Bates

Department/research group address: Tiyanjane Palliative care Clinic, Department of Medicine, Queen Elizabeth Central Hospital, P.O. Box. Box 95 Blantyre, Malawi.

Telephone: +265 999 295 802/+265 999 208 193/00 27 21 406 6590

Email: alex.chitani2013@gmail.com linda.ganca@uct.ac.za mjanebates@gmail.com

Name of Participant: ……..

Nature of the research: Qualitative

Participant's involvement:

What is involved? Interview

Risks: Answering some questions might cause an emotional response.

Benefits: The research study will provide disease understanding to patients.

Payment: Participants will not be given money as payment for being involved in this study

Circle Yes or No

1. I confirm that I have read or the information has been read and explained to me and I understand the information and have had the opportunity to ask questions. Yes No

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. Yes No

3. I agree to take part in the above study. Yes No

4. I agree to audiotaping of the interview Yes No

Signature of Participant _____ Date _____

Name of the Participant: _____

Signature of the person who sought consent _____ Date

Name of the person who sought consent_____

Signature of the researcher _____ Date: _____

If you have any further questions you can contact: *COMREC Secretariat, Malawi College of Medicine: Phone number: 01 871 911*

UCT Research Ethics Committee Secretariat Research, E 52 Room 24, Old Main Building, Groote Schuur Hospital, Observatory, Telephone: 00 27 21 406 6338

Appendix 6: KUPEMPHA CHILOREZO (CHICHEWA VERSION)

Dzina la kafukufuku: KUFUFUZA ZA CHISAMALIRO NDI ZINTHU ZINA ZOFUNIKIRA ZIMENE ODWALA ANGAKONDE KULANDIRA KUMAPETO A MOYO WAWO PA TIYANJANE PALLIATIVE CARE CLINIC, QUEEN ELIZABETH CENTRAL HOSPITAL, BLANTYRE, MALAWI.

Mayina a akuluakulu Ofufuza: Mr. Alex Chitani, Mrs. Linda Ganca and Dr. Jane Bates

Adiresi ya Ofufuza: Tiyanjane Palliative care Clinic, Department of Medicine, Queen Elizabeth Central Hospital, P.O. Box. Box 95 Blantyre, Malawi.

Foni: +265 999 295 802/+265 999 208 193/00 27 21 406 6590

Imelo: alex.chitani2013@gmail.com

Wotenganawombali: ……

Mtundu wa kafukufuku: Mafunso a pamaso ndi pa maso

Participant's involvement:

Zofunika? Kukambirana

Chiopsezo: Mafunso ena atha kupangitsa munthu kukhumudwa .

Ubwino: Munthu atha kumvetsetsa za matenda amene akudwala.

Malipiro: Wolowa mu kafukufuku sadzapatsidwa ndalama

Sungulizani Inde kapena Ayi pa funso lililonse.

1. Ine ndikutsikimiza kuti ndawerenga kapena andiwerengera ndikundimasulira za kafukufuku ameneyu ndipo ndamvetsa komanso ndinali ndi mwayi wofunsa mafunso.

Inde Ayi

2. Ine ndikumvetsetsetsa kuti sindiri okakamizidwa kutenga nawo mbali mu kafukufuku ameneyu ndipo ndili ndi ufulu wotuluka mu kafukufukuyu nthawi iliyonse, opanda kupeleka chifukwa, komanso kutuluka kwanga mu kafukufuyu sikudzakhuzana ndi chisamaliro chimene ndimalandira ku chipatala kuno. Inde Ayi

3. Ine ndavomera kutenga nawo mbali mu kafukufuku ameneyu.

   Inde Ayi

4. Ine ndavomera kuti zokambirana zonse zisungidwe mu makina osungira mawu.

   Inde Ayi

Saini wotenganawombali _____ Tsiku _____

Dzina la Wotenganawombali: _____

Saini ya opempha Chilolezo _____ Tsiku

Dzina la opempha Chilolezo_____

Saini ya Mwini wa Kafukufuku _____Tsiku: _____

Ngati mulindi mafunso ena Mutha kufunsa ku: COMREC Secretariat, Malawi College of Medicine: Nambala ya foni: 01 871 911

UCT Research Ethics Committee Secretariat Research, E 52 Room 24, Old Main Building, Groote Schuur Hospital, Observatory, Telephone: 00 27 21 406 6338

Appendix 7: Distress protocol

This distress protocol is for the research study titled: **An exploration of patients' preferences and priorities for the end of life care at Tiyanjane Palliative Care clinic, Queen Elizabeth Central Hospital, Blantyre, Malawi.**

All research participants will be fully informed about the nature of the topic to be covered in the interview. All patients will have the opportunity to halt the interview at any time if they experience discomfort of any kind. Patients will be allowed freedom and a choice to either terminate or restart the interview if they so wish. Arrangements have been made with Tiyanjane clinic management and permission received from them to have designated Tiyanjane palliative care team members who will offer support, counsel and/or debrief patients in the event that a patient becomes distressed.

Authorised by:

Name: Signature:

Witnessed by:

Name: Signature:

If you have any further questions you can contact: UCT Research Ethics Committee Secretariat Research, E 52 Room 24, Old Main Building, Groote Schuur Hospital, Observatory, Telephone: 00 27 21 406 6338 and *COMREC Secretariat, Malawi College of Medicine: Phone number: 01 871 91*

Appendix 7: NDONDOMEKO YA KAPELEKEDWE KA UPHUNGU (CHICHEWA VERSION)

Ndondomeko ya kapelekedwe ka uphungu mu ka mukafukufuku wotchedwa: **Kufufuza za chisamaliro ndi zinthu zina zofunikira zimene odwala angakonde kulandira kumapeto a moyo wawo pa Tiyanjane Palliative Care Clinic, Queen Elizabeth Central Hospital, Blantyre, Malawi.**

Anthu onse ofuna kudzalowa nawo mu kafukufuku adzawuzidwa za mtundu wa mutu wa kafukufuku umene udzakambidwe mwachimvekere. Odwala onse adzakhala ndi mwayi woyimitsa zokambirana nthawi iliyonse imene iwo adzawone kuti sangathe kupitiliza zokambiranazo chikukwa ali okhudzidwa kwambiri ndi mtundu wa zokambiranazo. Odwala adzakhala ndi ufulu ndi chisankho chopitiliriza zokambiranazo kapena ayi molingana ndikufuna kwawo. Chikonzero chakhazikitsidwa ndi mkulu wa Tiyanjane kiliniki ndipo chilorezo chapelekedwa kuchokera kwa iwo, chodzala ndi anthu awiri odzathandiza kupeleka chilimbitso, uphungu, ndiponso kumasula odwala ku zokambiranazo adzakapezeka kuti akhumudwa ndi zokambiranazo.

Wolamula:

Dzina: Saini:

Mboni:

Dzina: Saini:

Ngati mulindi mafunso ena Mutha kufunsa ku: UCT Research Ethics Committee Secretariat Research, E 52 Room 24, Old Main Building, Groote Schuur Hospital, Observatory, Telephone: 00 27 21 406 6338 ndi *COMREC Secretariat, Malawi College of Medicine: Nambala ya foni: 01 871 911*

Appendix 8: An interview guide

AN EXPLORATION OF PATIENTS' PREFERENCES AND PRIORITIES FOR THE END OF LIFE CARE AT TIYANJANE PALLIATIVE CARE CLINIC, QUEEN ELIZABETH CENTRAL HOSPITAL, BLANTYRE, MALAWI.

Opening statement: Thank you for agreeing to take part in this study. I am aware that the topic we are going to talk about today is a sensitive one that may evoke some painful or uncomfortable thoughts and feelings in you. I would like to let you know that you are free to respond in any way that you want to express your feelings. You may cry or be quiet for a moment if you feel a need to do so, that will be fine. You will not be blamed or judged for how you feel and how you express your feelings.

I would like to emphasize that this is a safe space for you to express yourself and the information gathered during this conversation will not be used against you or for anything else other than for the researcher's academic purpose.

1. To start our conversation, please share with me what you understand about your illness and care options. Why are you receiving care here at Tiyanjane clinic? (Objective 1, 2, 3, 4)

2. Share some of the thoughts you often have about your illness? (Objectives 1, 2, 4, 5)

3. Would you like more information on the thoughts or questions you have about your illness? (Objective 1, 2, 4)

4. What is the most important information you know OR would like to know about your illness and care options? Why is this so important to you? (Objective 1, 2, 3, 4)

5. How much involved have you been in making decisions about your illness including your health care needs and available care options? (Objective 2, 3)

6. At times when people are very sick they are concerned about what will happen to them if they get worse. When your illness gets worse what would you like those caring for you to do? E.g. would you like to be cared for in hospital or at home? (Objective 1, 4)

N.B Opting out question: (If there is silence after posing question **6**, **PAUSE.** Allow patient time to reflect.**)** Then proceed by asking: How do you feel about this question? Would you like to continue with this conversation? (If the participant's response is 'NO', then enquire whether he/she would like to speak to a counsellor OR you may offer that service and follow through their choice. Then skip to the **Closing statement.**)

7. Why is such preference (made above) important to you? (Objectives 1, 3, 5)

8. What would be the most important things you want people caring for you to remember and implement when your illness is getting worse? (Objectives 1, 3, 4, 5)

Closing statement: Thank you very much for taking part in this study and sharing your personal and sensitive information. Once again I want to reassure you that the information gathered during this conversation will be kept confidential and will not be used against you or for anything else other than for an academic purpose of this study.

If you have any further questions you can contact: UCT Research Ethics Committee Secretariat Research, E 52 Room 24, Old Main Building, Groote Schuur Hospital, Observatory, Telephone: 00 27 21 406 6338 and *COMREC Secretariat, Malawi College of Medicine: Phone number: 01 871 91*

Appendix 8 : NDONDOMEKO YA MAFUNSO A KAFUKUFUKU (CHICHEWA VERSION)

KUFUFUZA ZA CHISAMALIRO NDI ZINTHU ZINA ZOFUNIKIRA ZIMENE ODWALA ANGAKONDE KULANDIRA KUMAPETO A MOYO WAWO PA TIYANJANE PALLIATIVE CARE CLINIC, QUEEN ELIZABETH CENTRAL HOSPITAL, BLANTYRE, MALAWI.

Mau oyambirira: Zikomo kwambiri chifukwa chovomera kulowa mu kafukufuku ameneyu. Ine ndikudziwa kuti nkhani ya chisamaliro ndi zina zofunikira zimene munthu angafune kumapeto a moyo wake, si nkhani imene imakambidwa pakati pa a Malawi kawiri kawiri chifukwa anthu ambiri amakhulupilira kuti mwambo wa chi Malawi siwulola kukamba nkhani ngati imeneyi. Kukamba nkhani ngati imeneyi kumakhala ngati kulosera malodza. Nkhaniyi ikhonza kuyambitsa maganizo owawa ndi osowetsa mtendere mwa inu. Ndikukupemphani kuti mukhale omasuka zokambirana zathu. Mutha kuyankha mafunso mmene mungayankhire ndipo palibe amene adzakutsutseni. Mutha kulira kapena kukhala chete Kwa kanthawi ngati kuli kofunika kutero.

Ine ndikkukutsimikizirani kuti malo tili ano palibe wina otisokoneza ndipo mukhale omasuka kuyankha za kuhkosi kwanu. Zokambirana zathu zizagwiritsidwa ntchito ngati mbali imodzi ya sukulu Kwa munthu amene akuchita kafukufukuyu basi.

1. Poyambirira pa zokambirana zathu, Mutha kundilongoselereko za nthenda imene mukudwala? Kodi inuyo nthendayi mukuyimvetsetsa bwanji? Kodi ndi zisamaliro za mitundu yanji zimene mungalandile zokhudza matenda amene mukudwala? Ndi chifukwa chiyani mukulandira chisamaliro kuno ku Tiyanjane? (Cholinga choyamba, chachiwiri, Chachitatu ndi Chachinayi)

2. Kodi ndi maganizo anji amene mumakhala nawo pafupi ndi pafupi okhuza za kudwala kwanuku? (Cholinga choyamba, Chachiwiri, Chachinayi ndi Chachisanu)

3. Kodi mukufuna mutamva zambiri pa za maganizo ndi mafunso amene muli nawo pa za matenda amene mukudwala? (Cholinga Choyamba, Chachiwiri ndi Chachinayi)

4. Kodi uthenga wofunikira kwambiri umene mumadziwa wokhuza kudwala kwanu ndi wotani? kapena mungakonde mutadziwa za matenda amene mukudwala ndi mitundu ya zisamaliro imene ilipo? Kodi kudziwa za matenda anu ndi zisamaliro zake ndikofunikira bwanji kwa inu? (Cholinga Choyamba, Chachiwiri, Chachitatu, ndi chachinayi)

5. Kodi munapatsidwa mpata wochuluka bwanji wopanga zisankho zokhuza matenda amene mukudwala kuphatikizapo zosowa za umoyo wanu kuno ku chipatala? Kodi munapatsidwa mpata wochuluka bwanji posankha mtundu wa chisamaliro pa zisamaliro zosiyanasiyana zimene zimapezeka ku chipatala kuno? (Cholinga choyamba, Chahiwiri ndi Chachitatu)

6. Nthawi zina anthu akadwala kwambiri, amakhala okhudzidwa pazimene zizachitike kwa iwo tiyerekeza kuti matenda akula kwambiri. Nthawi imene matenda anu adzakafike pokula kwambiri kapena pa kaya kaya, kodi ndi zinthu ziti zimene mungadzafune kuti okusamalirani inu adzachite? Mwachitsanzo, mudzafuna kuti adzakusamalireni ku chipatala kapena kunyumba? (Cholinga choyamba ndi chachinayi)

Chidziwitso. Funso limene wodwala angaganize kuti ndilokhumudwitsa ndipo akufuna kutuluka mukafukufuku: (Ngati wodwala akhala chete atafunsidwa funso **la chisanu ndi chimodzi**, **WOFUNSA MAFUSO ADIKIRE KAYE.** Pelekani nthawi Kwa wodwala kuti aganizire za funso limeneli**).** Kenaka, Wofunsa mafunso atha kupitiliriza pofunsa kuti: Kodi inu mukumva bwanji mokhuzana ndi funso limeneli? Mungafunebe kupitiliza ndizokambiranazi? (Ngati munthu ayankha kuti 'AYI', funseni wodwala ngati akufuna kulankhula ndi a phungu aku Tiyanjane kapena Wofunsa mafunsoyo atha kupeleka uphungu ndi kutsatira zomwe wodwala akufuna. Dumphani funso la chisanu ndi chiwiri ndipo mupite ku **mawu otsiriza**.)

7. Kodi chisankho chanu mwasankha funso la mmwambali ndichofunika bwanji Kwa inu? (Cholinga choyamba, cha chitatu ndi chachisanu)

8. Kodi ndi zinthu ziti zimene zingadzakhale zofunikira kwambiri Kwa inu, zimene mudzafune kuti anthu okusamalirani adzakumbukire ndipo adzachite, pamene

mudzayambe kudwala kwambiri (Cholinga choyamba, cha chitatu, chachinayi ndi cha chisanu).

Mawu otsiriza: Zikomo kwambiri potenga nawo mbali mu kafukufuku ameneyu ndi pogawana nane za kuhkosi kwanu. Ine ndikutsimikizanso kachiwiri kuti zokambirana zathu zidzasungidwa mwa chinsinsi. Zokambiranazi zidzagwiritsidwa ntchito mu kafukufuku wa sukulu basi.

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