DISSERTATION

An exploration of Doctor's perceptions and the provision of Palliative Care at a Private Hospital in Gauteng, South Africa.

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DECLARATION

I, Elizabeth Cecile Booth, hereby declare that the work on which this dissertation 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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ACRONYMS

AIDS:	Acquired Immunodeficiency Syndrome
CINAHL:	Cumulative Index to Nursing and Allied Health Literature
COPD:	Chronic Obstructive Pulmonary Disease
EBSCO:	Elton B. Stephens Co – collection of databases
GSH:	Groote Schuur Hospital
HAU:	Hospice Africa Uganda
HIV:	Human Immunodeficiency Virus
HPCA:	Hospice Palliative Care Association of South Africa
HREC:	Human Research Ethics Committee
MEDLINE:	Medical Literature Analysis and Retrieval System Online
NPFSPC:	National Policy and Framework Strategy in Palliative Care
NSCLC:	Non-Small Cell Lung Cancer
PALPRAC:	Association of Palliative Care Practitioners of South Africa
RCT:	Randomised Control Study
SA:	South Africa
UCT:	University of Cape Town
UK:	United Kingdom
US:	United States
UWCM:	University of Wales College of Medicine
WHA:	World Health Assembly
WHO:	World Health Organisation
Wits:	University of the Witwatersrand

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ABSTRACT

Introduction: Palliative care is a core component of comprehensive health care across a person's life span. South Africa is currently in the process of integrating palliative care into all levels of the health care system. Doctors play a vital role in providing these services, but misconceptions about palliative care and who should be providing it, may prevent these services from being offered.

Aim: The aim of this study was to discover doctor's perceptions and the current provision of palliative care in a private hospital.

Objectives: The objectives of the study were: (1) to explore doctors' experiences of pain and symptom management in palliative care; (2) to explore doctors' perceptions of palliative care, goals of care and teamwork in palliative care; and (3) to explore the doctors' provision of palliative care at the hospital.

Methodology: This was a qualitative study using a grounded theory approach. Semi-structured interviews were conducted with 14 participants, made up of doctors in oncology, physicians, surgeons, a cardiologist, an intensivist, a hematologist and a general practitioner. Interviews were recorded, transcribed and an inductive process was used for data analysis which allowed for categories to emerge from the data._

Results: Eight themes emerged from the data analysis: improving the quality of life; palliative care as a role for oncologists; late referrals to palliative care, views on the World Health Organisation analgesic pain ladder; morphine a controversial means of pain control; team approach; family involvement and spiritual care.

Conclusion: Palliative care was seen as an important intervention for a dying patient, but by introducing these services so late, patients are not benefitting from all that palliative care has to offer. Doctors did not always have a good understanding of when and how to provide palliative care. The following recommendations were made: (1) further research to be conducted in more private hospitals; (2)engage with management and doctors to begin the process of offering more formalised palliative care services at the hospital; (3) networking with available palliative care services, (4) organising palliative care training and workshops and (5) palliative care awareness campaigns.

CHAPTER ONE: INTRODUCTION

Doctors play a vital role in providing palliative care, however, misconceptions about what palliative care truly is, have resulted in doctors not always realising the central role that they can and should play in this regard. In 2014, at the World Health Assembly (WHA), Resolution 67.19 was adopted. This resolution states that palliative care is a core component of comprehensive health care across a person's life span and urges member states, including South Africa, to integrate palliative care services into their health care systems (1). A requisite for the integration of palliative care into health systems therefore should be that all doctors be equipped with the basic principles of palliative care.

This study has been borne from the researcher's observations and experiences of service delivery whilst working in a private hospital setting. These experiences have developed in the researcher a quest to discover whether patients attending a private health care facility in South Africa are offered adequate palliative care options and services, or not. After reviewing the recently adopted National Policy and Framework Strategy in Palliative Care (NPFSPC), the need to conduct the study was raised even more (2). Before exploring what the current position of palliative care is in South Africa, it is important to firstly look at some of the concepts of palliative care and end-of-life care.

1.1 Concepts of Palliative Care and End-of-Life Care

The concepts palliative care and the end-of-life care are similar, but they are not the same. The end-of-life care is one portion of palliative care, where the patient is nearing the end of their life, although this is difficult to predict, medically it usually refers to a patient who has about six months left to live. The main goals at this stage is to ensure that a patient's quality of life is *maintained* and that they die with dignity. Palliative care however aims to *improve* a person's quality of life, as it is an approach that can be introduced when a patient is diagnosed with a life-threatening illness, and should be part of the patients continuum of care throughout their illness, so that a patient and their family's physical, emotional, and spiritual needs are actively addressed (3).

However, with its origins firmly rooted in the hospice movement, where the main population group was traditionally cancer patients entering the dying stages of their disease, palliative care has continued to be viewed, by many in the medical community, only as end-of-life care (4). Palliative care is therefore incorrectly perceived as a treatment that occurs at a specific time, namely at the end of a patient's life, when treatment shifts from active treatment, where a cure is still a possibility, to palliative treatment, where a cure is no longer possible and the *curative team* has run out of treatment options. A qualitative study conducted in the United Kingdom highlighted how acquiring knowledge about palliative care is only one step towards changing the way one practices. Doctors in this study had a understanding of the wider concept of what palliative care is, but did not always see palliative care as a discipline in which they should be playing a role, as palliative care is often still seen an intervention for the management of a dying patient (5). Doctors may believe that their focus should be on curing their patient. It is important to also explore what South African doctors' understanding of palliative care is, as well as the role they feel they should or should not be playing in providing it.

1.2 What is Palliative Care?

The World Health Organisation (WHO) defines palliative care as an approach which aims to improve the quality of life of a patient, as well as their families by ensuring that the suffering of the patient is prevented and relieved by early identification and impeccable assessment and subsequent treatment of pain and other problems, namely physical, emotional, social and spiritual (6). Palliative care can take place from the moment the doctor makes their first contact with a patient, whether it is at the early stages of an illness, or when it becomes incurable. Appropriate provision of palliative care is that patients diagnosed with a life-threatening illness should be offered palliative care at diagnosis alongside curative interventions (3). If palliative care aims to improve the quality of life of patients and their families, providing these services at the very end stage of a person's life, defeats the fundamental purpose of palliative care.

1.3 Palliative Care versus Futile Treatment

Futile treatment has been defined as an intervention that no longer benefits a patient, has the potential to cause harm, does not achieve a goal and lacks any real benefit to justify the use of valuable resources (7). The challenge remains that doctors do not want to give up on their patients. Some doctors have stated that they see every death of a patient as a failure, hence they may pursue futile treatment in the hope that they may still be able to cure the patient (7). There needs to be a shift in this type of thinking, from simply pursuing a cure at all costs, to healing a patient. This involves a movement from high-tech investigations and treatments which result in low touch, to rather low tech investigations that promote high touch (8).

A question that needs to be explored further, is whether doctors are being trained to cure or heal? Good medicine is not simply curing a patient, but rather offering them total care by ensuring that the health care professional treats their total pain, a concept that was coined by Dame Cicely Saunders (9).

Dame Cicely Saunders, founder of the modern hospice movement recognised that the care of a dying patient was inadequate in the hospital setting, and so founded the first hospice, St Christopher's in 1967, in order to address the needs of dying patients in a more holistic way (9). Saunders used scientific evidence to argue that a palliative patient's pain was multidimensional and included not only physical pain, but also emotional, social and spiritual pain too (10). This is what she referred to as a patient's "total pain". Saunders went on to say that it was not possible to obtain optimal pain relief, unless all these dimensions are addressed (10). It is therefore important that doctors offering palliative care provide optimal pain relief to patients, whatever the dimensions of the pain may be. However, even during this time, and a decade after Saunders died, doctors still recommend or provide futile treatment that is not beneficial to the patient or to their family (7).

Doctor Edward Trudeau in the early 1800s already acknowledged that doctors only sometimes cure, and a little more often they relieve, but that they always need to play a role in comforting their patient (11). However, doctors have remained focused on a cure, even though the Hippocratic oath says, "I will use treatment to help the sick…" It remains a difficult transition for doctors to shift their thinking from seeking a cure, to have to *relinquish control* over the disease's progression. This often may feel as if they have to move from playing an active leadership role, to that of a helpless bystander (12). Palliative care is not a call to "withdraw care" but rather to shift ones focus from being diseased-centred to being patient-centred. This calls for a change in their focus from wanting to prolong the patient's life at any cost, to rather focusing on a life that has good quality(12). In order to ensure that a patient has a good quality of life, the starting point needs to be effective communication between the doctor and the patient.

1.4 Communication

Effective communication between a doctor and a patient is key in order to ensure that a patient understands the prognosis, the purpose of care, has realistic expectations and knows what the goals of the treatment are. This allows a patient to be a full participant in terms of their own health care. Good communication has been shown to improve the care that a patient receives, and allows a patient to disclose important information, which leads to good total pain control (10,13).

Doctors still struggle to disclose all the information to their patients (13, 14). Doctors have stated how they often do not have the time they need to adequately address the emotional needs the patient has after having a difficult conversation, leading to the avoidance of such discussions (13). Some doctors also believe that their patients do not want to know the whole truth about their prognosis, because if they do know the truth it will be too overwhelming for them, and they will spend the time that they have left being extremely depressed (14). However, studies have shown that the unknown is often scarier than the known. Hope is not based on a patient's ignorance, but on the knowledge, they have (14). If doctors avoid the challenge of telling the truth, or do not have the time to engage in these important conversation, they can also play a role in preventing a patient voicing their fears and their worries, thus leaving their patient feeling isolated (13, 14). This is why open and honest communication is essential in improving the patient's quality of life.

It remains extremely challenging for a doctor to discuss the withdrawal of a curative approach, and moving more towards palliation, a more symptomatic and total pain approach (14). Doctors have acknowledged how difficult these conversations are for them, and studies have even revealed a decline in a medical student's communication skills, as they progress through their studies (13, 14). There seems to be a need for more training in communication at both undergraduate and post-graduate levels for doctors (14).

Hearing the truth about one's poor prognosis can be devastating, but it can also lead to important conversations around a patient's fears, and discussing their dreams, allows them the opportunity to decide where they may want to die, get their affairs in order and also stop them from wanting to pursue futile treatment (14). Good communication will lead to good care, which leads to good total pain control. The burden of care does not lie with the doctor alone, as open and honest discussion around a patient's illness opens the door to involving the multidisciplinary team in addressing the total pain of a patient (10, 14).

1.5 Palliative Care Involves a Team Approach

Caring for a patient is multi-dimensional, as highlighted by Saunders, when she first spoke of a patient's total pain: physical, psychological, social and spiritual. In order to provide the maximum comfort, support and total pain control which a patient needs, a team approach with a variety of disciplines, knowledge, skills, experience and creativity is required. The WHO's definition of palliative care also highlights the need for a team approach in order to address the needs of patients and their families (15). The palliative care team may include: doctors, nurses, social workers, physiotherapists, dieticians, chaplains and other allied health professionals (16). Team work is integral in providing good palliative care to a patient and their family (16, 17).

An effective palliative care team needs to have a nurturing organisational environment (17). A nurturing organisational environment is one in which open communication is encouraged between team members, irrespective of the hierarchy of each individual, helpful contributions are acknowledged, mistakes are seen as learning opportunities and team achievements are celebrated. Effective palliative care teams also need to include patients and their family as members of the team. The patient is considered the head of the team, and needs to be the one who makes the final decision, based on the information and the support that they have received, as well as their own values that guide them (16, 17).

It has been found that a team will function the most effectively when it has gone through the developmental stages of *forming, storming, norming and finally performing,* when optimal functioning is usually achieved (17). During the forming stage, the team does not have a shared vision yet and they usually rely on a dominant member, often it will be the doctor. Storming or the conflict stage is when the members of the team have different opinions on how the group should be functioning. With time the team develops more cohesion and consensus, a shared vision for the team is established, this is also known as the norming stage. This leads to the *performing* stage-where leadership will be varied from one meeting to the next, and there should be open and honest communication between the different team members. Assigning a team’s role is based on skills and expertise, and the team has a sense of unity, as they strive for a common goal of improving a patient’s quality of life, by ensuring that they address total pain. Team work however, is not smooth sailing, it comes with challenges and barriers (17).

Literature on teamwork has identified several barriers to building effective teams in health care. Barriers which this study will explore include communication, power relations, hierarchy and role blurring. Communication remains a challenge, not only between doctors and patients, but also between team members. Varied terminology between different members of the team can lead to confusion amongst team members, that can also have a negative impact on patient care (18). Communication is further burdened by *power relations* within the team. Power relations often play out when some members of the team assert their own profession as superior, resulting in them ignoring the perspectives of the other team members. This prevents team collaboration from taking place and may negatively impact the team's role of ensuring that the patient receives the best quality of life (18). For example, in a hospital setting the doctor's perspective may often be seen as the most important. This may lead other team members to not freely share their view whereas collaborating may ensure the best care for a patient.

There is a constant battle between *health care hierarchy vs the democratic team structure* called for in palliative care teams (18). The patient, and not the doctor or any other member of the team, remains the expert of what they consider as a good quality of life. The patient is therefore the decision leader and they remain at the centre of the palliative care team. While this hopefully leads to the patient's needs being met, it can also result in role confusion, as this renders the role of a team leader as redundant. Role blurring can also occur, causing conflict between team members, as each individual member tries to promote their own professional identity within the team, often preventing the provision of optimal support for a patient, which is one of the main goals of the palliative care approach (18). The paragraphs above highlighted the fundamental position which effective communication has in palliative care and focused more on its impact in providing efficient palliative care services. One then wonders what the current position of palliative care is in South Africa as literature suggests that globally there continues to be a lack of resources, policies and trained palliative care practitioners to provide good health care to patients with life-limiting illnesses (19).

1.6 The Position of Palliative Care

1.6.1 Globally

Governments worldwide still focus the majority of their health policies and strategies on curative medicine, and many still do not provide basic palliative care training for their medical students (20). Added to this is the increasing age of the general population, and already thinly stretched palliative services. With an increase in age, there is an upsurge or a rise in chronic illnesses, e.g. renal failure, diabetes and non-communicable diseases such as dementia, cancer and heart disease which increases the need for palliative care substantially (21). Even in countries where palliative care is well established, like the United Kingdom (UK) and the United States (US), where the pressure to continually increase the available palliative care services remains (21). Wealth also continues to play a role in the ability of a country to provide good palliative care, as the ranking of the quality of death index revealed a clear association between income and a nation's ability to offer good palliative care. There were however countries with limited income who were making significant strides in palliative provision, such as Panama and Uganda (22). Income is clearly not the only factor influencing the provision of good palliative care.

The four key areas in the public health strategy for palliative care which were identified by Jan Stjernsward and endorsed by WHO focuses on: education; the development of health policies; access to essential palliative care medicines; and the implementation of palliative care services (23). Has the public health strategy for palliative care had an impact on the development of palliative care in Africa?

1.6.2 Africa

Africa, in contrast to the rest of the world, whose general population is ageing, has a life expectancy of only 53 years, which is about 15 years less than the global average (24). HIV/Aids continue to be the leading cause of disability, and its prevalence among African adults is the greatest disease burden worldwide. The prevalence of cancer and other non-communicable disease continues to rise, increasing the disease burden (24, 25). Palliative care development across the region is even more important to ensure that even if there is a lack of available treatments, patients at the very least should die a pain free and dignified death (24). Africa's high morbidity and mortality rate is one of the multiple challenges that palliative care development is facing on the African continent alongside the lack of palliative care education, limited availability and/or accessibility to morphine, a lack of resources, funding and poverty (26).

Despite these challenges, palliative care has shown steady growth in Africa over the past decade. This growth has taken place due to the implementation of some of the four focus areas recommended in the public health strategy for palliative care, mentioned earlier. For example, Kenya has made huge strides in palliative development through the increase in palliative services and the introduction of palliative care specialised courses (20). Uganda has also made ground-breaking improvements to their provision of palliative care, by allowing registered nurses and clinical officers, who are certified palliative care specialists, to prescribe opioids. Hospice Africa Uganda (HAU), who initially brought palliative care to Uganda, has educated and trained over 8000 nurses, physicians and volunteers in palliative care since 1993 (27).

Kenya and Uganda, together with South Africa (SA), stand as beacons of hope in Africa. All three of these countries did however not excel in all four dimensions of palliative care outlined by the WHO, and so even these high-preforming countries have areas in which they need to grow (27).

The reality remains that vital pain medication is still not available in most African countries. In a survey conducted by Rhee, et al. to determine the development of palliative care in African countries, it was found that one-fifth of the participating countries had no palliative care services at all (24). The hope is that other African nations will begin to implement strategies similar to SA, Uganda and Kenya, as the need for palliative care will continue to grow. SA is actively developing its palliative care component within its health care system, to ensure its continued growth.

1.6.3 South Africa

SA is considered one of the top three ranked African countries in palliative care development and is preforming well in several area (21,24). SA is ranked the highest consumer of opioids in Africa, due to the focus placed on Primary Health Care in SA, resulting in important palliative care drugs such as morphine, being declared an essential drug. This is encouraging as it suggests that pain management is considered a priority in health care delivery in the SA health system. Another encouraging development in SA is that a national plan for pain control is also in place (24, 28). Palliative care education at medical institutions has also grown through the years, with the University of Cape Town (UCT) and the University of the Witwatersrand (Wits) providing palliative training at various levels. The University of Stellenbosch has also started to offer palliative care courses and modules (29). The one area that was lacking in previous years was a stand-alone palliative care policy. The benefits of such a policy usually leads to improved palliative care services, as well as better access to such services (2). The quality of death index also stated that high ranking countries on the index had all effectively implemented a national palliative care policy framework (21).

In response to the WHA resolution 67.19 (2014) a *National Policy Framework and Strategy on Palliative Care* (NPFSPC) was developed, finalised and adopted in August 2017. The policy highlighted five main goals, one of which is closely related to the topic of this study. The goal identified the need to ensure adequate numbers of well-trained health care providers who are able to deliver palliative care services at all levels of the health care system (2). The policy acknowledges that due to the lack of a policy in the past, palliative care was delivered ad-hoc, which led to poor communication and the poor linking of necessary services, resulting in large gaps, and preventing comprehensive palliative care being offered to patients (2). Doctors did not always receive the necessary training, resulting in a lack of knowledge about essential palliative care medicines, like morphine, which has prevented the provision of good pain management. Despite SA having the highest consumption of opioids in Africa, and the acknowledgement of the importance of good pain management, there still seems to be a gap between policies put in place, and the knowledge or the confidence doctors currently have to prescribe these medications. The policy hopes to close this gap and change the commonly held view that palliative care equates to end-of-life care. Rather it should be seen as a basic human right that has not been achieved yet in many countries, including SA, and must be part of the comprehensive care of a patient, not only at the end of their lives, but throughout the life course (2).

In 2007, Brennan explored the various calls for palliative care to be considered as an international human right (19). The relief from suffering is a goal held by both medicine and human rights, but the reality is that the right to health cannot be absolute due to the significant differences in resources throughout the world. Therefore, the right to health is aspirational, and so too the right to palliative care, it is something that is hoped and aspired towards over time. Brennan went on to say that what one needs to strive towards is free access to palliative care for all cancer patients as a fundamental right (4) and this may as well include all patients facing life-threatening illnesses.

1.7 Providing Palliative Care at all Levels of Care within the South African Health System

Access to palliative care in SA for all patients facing a life-threatening illness will be achieved by providing palliative care at all levels, namely primary, secondary and tertiary levels of care. Although in SA primary care is mostly promoted, secondary and tertiary health care teams are also needed to support and to strengthen primary level care teams. This therefore calls for palliative care to be delivered on two levels, namely a basic level of palliative care and a specialised palliative care level (15, 3). The basic level entails pain control and the management of general symptoms, which should be provided by all healthcare professionals. If every patient has the right to receive palliative care, every doctor is responsible for providing it (30). *A specialised palliative care level*, is made up of a multi-disciplinary team that addresses more complex and persistent symptoms and problems experienced by a patient (19). Health care provision and palliative care within the South African context face several challenges, which are further complicated by the lack of resources in most settings, and the fact that health care is provided in both public and private settings. Public health facilities are mostly used by the majority of the population (84 percent), as only 16 percent if South African belong to a medical aid scheme (31).

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

While reviewing the current available literature on palliative medicine, it became clear that there is a growing knowledge base of palliative medicine, as well as the development of policies to hopefully begin the process of the wide-spread implementation of palliative medicine.

A review of the literature that is related to your research topic is important in order to ensure that one has a good understanding of the topic, to discover what has already been researched on the topic and to know what the key issues are (32). One also discovers the theories that are currently being applied and developed, as well as any criticisms (32, 33).

A literature search was conducted during the process of writing up this research study. The literature search used EBSCOhost and Google Scholar. The search for literature through EBSCOhost the following databases were chosen, Africa-Wide Information, CINAHL, Health Source: Nursing/Academic Edition, MEDLINE and PsycARTICLES. Articles and statistics of interest mentioned in journal articles and then located in the reference list, were also searched and accessed through the use of Google Scholar.

The key words that were searched for were: ‘palliative care’ ‘palliative medicine’ AND ‘doctors perceptions’; ‘palliative care’ AND ‘doctors roles’ OR ‘doctors provision’; ‘palliative care’ AND ‘human right’; ’palliative care’ AND ‘right to health’; ‘palliative care services’ AND ‘public hospitals’ OR ‘private hospitals’ AND ‘South Africa’.

Research has been conducted in Australia, Germany, the United Kingdom, the United States of America, and the public hospital setting in South Africa, to gain a better understanding of doctors’ perceptions and the provision of palliative care, as well as when it is best to introduce it. In SA, more research needs to be conducted with a wider specialty of doctors, including those in private hospital settings where there seems to have been a lack of palliative care related research. The literature reviewed will be presented under the following headings:

- Pursuit of futile treatment.
- Misconception of Palliative Care as End-of-Life Care by health professionals.
- The Role of Doctors in Palliative Care.

- Doctors' Palliative Care training.
- Provision of Palliative Care: Public vs. Private Hospitals.

2.2 Pursuit of Futile Treatment

Willmott et al. (7) in 2016 conducted a qualitative research study using in-depth interviews in three tertiary public hospitals in Australia, in which they explored the reasons why doctors provide futile treatment at the end of life. In their study they mention that there is a growing body of evidence worldwide that futile or inappropriate treatment is being provided to adult-patients, when they are actually at the end-of-life stage. They go on to highlight that such treatment not only prolongs a patient's suffering, but also wastes scarce resources in the healthcare setting (7). In a country like SA, where resources are already scarce, and there is also an in-balance of available healthcare, it is important that all available resources are used as appropriately as possible. In order to reduce/prevent futile treatment, there needs to be an understanding of why a particular treatment is being offered in the first place. The study highlighted three main reasons why futile treatment is provided. Firstly, doctors are trained to cure. Secondly doctors found it easier to ask a patient's family if they want everything to be done, rather than sit with the family and have a difficult conversation, usually resulting in patients and their families requesting continued treatment. Lastly, organisational barriers within hospitals prevent patients from being moved from curative treatment to palliative care (7).

A study by Hanratty et al. (2002), conducted a focus group with doctors to examine their perceptions of palliative care as an intervention for patients in heart failure (34). The doctors in this study were made up of general practitioners and consultants in cardiology, general medicine, geriatrics and palliative care. Their study found that although most doctors acknowledged that palliative care was important, that they still avoided these difficult conversations with their patients, due to the unpredictable nature of chronic heart disease. Doctors were concerned about the possible negative impact of giving bad news too early, and what effect that could have on their patients, such as patients losing faith in their doctor or giving up. Doctors therefore continued with treatment that was often futile (34). Although the doctors did acknowledge that open communication in the terminal care phase was beneficial, there was still an unwillingness to engage in these challenging conversations (34). Both Wilmott and Hanratty's studies point to the doctors' struggle to have open communication with both patients and their families, and that this impacts on treatment decisions (7, 34).

Fallowfield et al. (2002) wrote a paper which looked at communication in palliative care (14). Their paper explored the impact of doctors accidental or deliberate attempts to disguise the truth. To demonstrate such attempts by doctors, they used extracts which were taken verbatim from interviews, as well as cases of unintentional deception or misunderstandings caused by the ambiguous language that doctors sometimes use. They also provided evidence from research studies that show that although the truth may hurt, deceit hurts more (14). Fallowfield et al. found that worldwide doctors underestimate the information needs of their patients (14), a conclusion that is supported by findings in a study conducted by Jenkins et al. (2001) which focused on patient information needs (35).

Jenkins et al. (2001) conducted a study in the UK to examine the information preferences of a heterogenous sample of 2331 patients with cancer (35). It is important to note that the information needs between the participants in this study were not different between patients receiving curative or palliative treatment, or even for patients in remission. Information preferences were assessed by making use of an adaptation of *Cassileth's Information Needs questionnaire* and it was found that 87 percent of patients participating in the study would want to know all possible information, whether it be good or bad news (35). However, doctors continue to argue that patients do not want to know the truth, as the truth could be too overwhelming for a patient, and could cause them to become depressed and to feel hopeless (14). The opposite was however found in Jenkins et al., in which it stated how providing patients with information according to their own agendas, actually improves psychological adaptions to their illness and to the treatment that they need to receive (35). The study also found that 98 percent of patients wanted to know whether their illness was cancer and 95 percent of patients wanted to know if they could be cured. These findings show that doctors should not be withholding the truth of both a patient's diagnosis and prognosis. The high percentage of patient responses in this study, who want to be informed about their illness highlights the gap that needs to be addressed as suggested in findings by Fallowfield et al. which indicate that doctors underestimate the information needs of their patients. Healthcare professionals should rather start looking into developing the communication skills they need, to provide the information that patients want, in a sensitive and in a flexible manner (35).

In their study, Best et al. (2014) examined the role of doctors in helping a dying patient find peace. Best et al. conducted semi-structured interviews with 15 cancer patients who had advanced disease, in various care settings (36). The study revealed that open and honest information from the doctor to the patients, gave the patients a sense of peace, as was found in the Jenkins et al. study, and in contrast of the study findings by Fallowfield et al. as stated previously. In Best et al.'s study, patients had a good understanding of their prognosis and could make the necessary plans leading up to their death. They were also able to explore their fears, which helped to facilitate a good death. By having these honest conversations, patients felt that they could reset their goals of care together with their families, which prevented futile treatment being offered and rather improved the quality of life (36). The challenge for doctors remains whether they feel comfortable and equipped with the necessary communication skills, to engage in these tough conversations, and what do they perceive their role to be in providing palliative care?

2.3 Misconception of Palliative Care as End-of-Life care by Health Professionals

Hanratty et al. (2006) conducted further research, again making use of focus groups, in which they explored a doctor's understanding of palliative care (5). Previously their research looked at doctor's perceptions of palliative care for heart failure patients, but now they wanted to look at doctors' perceptions of palliative care, due to the call for palliative care to be available to a broader category of patients. The focus groups were made up of doctors in cardiology, general practice, palliative care, geriatrics and general medicine. Palliative care was seen by many of the doctors in this study, as care that occurs at a specific point where there is almost a change in gear from trying to keep someone alive, to looking more at keeping them comfortable (5). This view places palliative care firmly in the category of end-of-life care. Palliative care was incorrectly perceived in this study as a treatment that occurs at a specific point, when treatment shifts from active treatment, whereby cure is still a possibility, to palliative treatment, when cure is no longer possible and the curative team has run out of treatment options. Leading doctors in this study view palliative care as a discipline in which they should not be playing a role in, as they continue to view it as the management of a dying patient, and they see their role as curing a patient at all costs (5).

In their paper written back in 1995, Jecker and Schneiderman explored the request of families that *everything possible be done*, that caring should not only be introduced as the primary intervention when a patient can no longer be cured. Rather, caring and curing should actually operate in tandem, as any ill patient needs compassion, emotional support and painful symptoms to be relieved, even when having potentially curative treatment (37). The cases and the literature reviewed for this study, suggested that palliative care should be introduced together with curative treatment, and all doctors can and should play a role in providing it (37).

2.4 The Role of Doctors in Palliative Care

Traditionally, palliative care was seen as an intervention introduced to cancer patients with an advanced illness, in which their oncologists would treat a patient late into the course of their illness, and then be abruptly moved towards a more palliative approach (38). Irwin et al. (2012) reviewed a number of studies and literature that explored the possible survival benefits early palliative care interventions have. Irwin et al. went on to present the findings of the potential for improved survival in metastatic non-small cell lung cancer (NSCLC) patients who were offered concurrent standard oncological treatment and palliative care, from the time of their diagnosis (38). The study found that all these patients had an improved quality of life and there was also an improvement in their overall survival. Potential reasons for the improved survival was due to the patient's total pain being addressed by palliative interventions (38). As previously mentioned, palliative care focuses on addressing the total pain of a patient and their family, namely their physical, emotional, social and spiritual pain. The hope is that a patient's best possible quality of life is promoted according to their preference (38).

Irwin et al. reviewed the current literature on the potential survival benefits of early palliative care. A Randomised Control Trail (RCT) by Temel and colleagues was reviewed. The study was made up of 151 patients who were newly diagnosed with metastatic NSCLC were recruited from a thoracic oncology clinic and assigned to either standard oncology care or to early palliative care, within eight weeks of being diagnosed (38). The main focus of the trial was quality of life after twelve weeks. Other outcomes assessed were mood (specifically anxiety and depression), understanding of the diagnosis and how aggressive care was at end-of-life. The study found an improvement in the quality of life and depression after twelve weeks, as well as a more accurate understanding of the diagnosis, and more patients had documents put in place in terms of resuscitation preferences and patients opting for less aggressive care at the end-of life phase (38).

A second RCT discussed by Irwin et al., was a nurse led intervention with 322 newly diagnosed patients with advanced cancer, including NSCLC patients (38). Patients enrolled in the study were randomly assigned to usual care or usual care together with telephone-based intervention. Nurses would contact the second group of participants on a weekly basis in order to provide education, problem solving, any communication or social support system struggles, ensuring that symptom management took place and help to set up an advanced care plan together with the patient. Patients were followed-up at least once a month, until the end of the study or the time of death. Their families were also offered support at a monthly group session run by a nurse practitioner and a palliative care physician. The aim of this intervention was to encourage both patients and their families to be more involved in their own care. The primary outcome was quality of life, which was higher in the intervention group, as well as symptom intensity and the use of health care resources, both of these did not show significant changes. A secondary outcome was mood, as there was a decrease in depression in the intervention group. A post analysis of the study found that there was a non-significant increase in survival between the intervention group of 14 months versus usual care which was 8.5 months (38).

Irwin et al. also briefly mention a study conducted by Sloan et al. in which 2442 patients with NSCLC were involved in a study in which they wanted to investigate if a patients quality of life, measured by a simple single item within six months of being diagnosed, has an impact on a patients overall survival (38, 39). Sloan et al.'s study found that there was a significant relationship between a patient's overall quality of life and their survival. Sloan et al. recommended that further studies be done to see how deficits in the quality of life can be addressed, in order to improve a patient's overall survival (38, 39). The answer to this may simply involve introducing palliative care from a diagnosis, as it focuses on improving a patient's quality of life (39).

The studies reviewed above begin to point to a vital role that doctors can play in palliative care, as physical symptoms have a negative impact on a patient's quality of life. Rabow et al. (2004) conducted a RCT study, in which they looked at patients who continued to seek treatment for their underlying disease, while receiving outpatient palliative medicine consultations (40). The study was made up of 50 intervention patients, and 40 control patients. The patients were referred by their treating primary care physicians and consisted of patients with advanced congestive heart disease, chronic obstructive pulmonary disease (COPD) or cancer, and who had a prognosis that ranged from 1-5 years (40). The study found that although the intervention group patients had less dyspnoea (shortness of breath) and anxiety, there was not a significant improvement in pain and depression (38, 40). The study stated that the primary care providers prescribed the recommended opiates in only 8 percent of patients and only 18 percent of patients received the anti-depressant that they needed (38, 40).

Irwin et al. included Rabow et al. in their review and stated how the investigators suggested that in order to improve a patient's quality of life, that you needed to address a patient's pain and depression (38, 40). Irwin et al. added that this study also highlighted the need for palliative care physicians to provide direct patient care, which would also call for an improvement in the communication and in the care co-ordination with the patient's primary medical team (38).

Irwin et al.'s review of a number of studies, revealed that by focusing on a patient's quality of life, doctors can even increase their patient's overall survival. Doctors can do this by addressing a patient's pain and overall symptom burden, as well as depression. Doctors can also ensure that their patients have an accurate understanding of both their diagnosis and their prognosis, which assists patients in their treatment decision-making process. Patients are then able to receive less aggressive and sometimes prevent "futile" treatment when moving into end-of-life care, as they are referred to hospice earlier (38).

From the studies reviewed above, a conclusion therefore may be drawn that by ensuring that palliative care is part of the comprehensive care of a patient, will result in multiple benefits to the patients and their families, which could even make difficult conversations between a doctor and a patient a lot easier. All healthcare professionals should confidently provide palliative care alongside active treatment (38). The role of the doctor in palliative care remains symptom controls, as well as open and honest communication with the patient and their family (41). However, doctors seem to struggle with the task of offering palliative care to their patients, and this may be more than simply their desire to cure their patients.

2.5 Doctor's Palliative Care Training in South Africa

Gwyther et al. (2007) wrote an article that described the development of the postgraduate palliative medicine program that was being offered at the University of Cape Town (UCT). It stated that in SA, palliative care was initially provided from 1980 by hospices, which were run by a multidisciplinary team made up of professional nurses, social workers, pastoral counsellors and volunteers. Hospices relied on general practitioners volunteering their services when possible. SA doctors had at that stage not yet received any formalised training in palliative care, and many doctors felt isolated and inadequate, as they wanted to be able to access the advice that they needed from a palliative medicine specialist (42). UCT recognised the need to provide doctors in Africa with the skills that they needed to address the ever-growing number of patients facing terminal illnesses (42). UCT developed a postgraduate distance palliative care program for doctors in 2000 (42). This was the first postgraduate palliative program on the African continent. The program was developed in collaboration with UWCM (now known as Cardiff University), who were the first university to introduce palliative courses in 1989. This collaboration led to the introduction of the first palliative care program offering the skills and the knowledge needed for the South African Medical community (42).

Gwyther et al. went on to discuss the evolving of the palliative education that was taking place in SA. Initially a UCT program was offered to hospice doctors, but from 2001 to 2007 a total of 139 doctors from a variety of specialties had registered for the course, and 72 of those had already graduated with an MPhil in Palliative medicine. In 2003, the first postgraduate students from outside SA enrolled in the postgraduate program. Leading from the success of the postgraduate program, a six-month distance learning course was developed by Hospice Palliative Care Association. It was called "Introduction to Palliative Medicine" and was offered to experienced doctors, nurses, social workers, spiritual counsellors and other health care professionals. The goal of this short palliative medicine course was to provide a platform for previously qualified professionals with an opportunity to enhance their palliative care knowledge and skills, and to be guided into the transference of this learning into their workplace (42).

Carla et al. assessed the postgraduate palliative care distance learning program offered by UCT, using a mixed-method approach (43). Two surveys were conducted, that made use of open-ended and multiple-choice questions, from January to December 2007. All students registered in the program from 2000-2007 were eligible to be part of the study. The researchers wanted to assess the impact that the program had on the health care practices of the participants, as well as the wider community (43). The findings from the graduate survey showed that the participants felt that the course progressively altered their understanding of how to care for a patient with a life-limiting illness, and reported a variety of ways it affected the healthcare system that the students worked in. The only area that participants felt had room for improvement was the lack of a practical component (43). Participants felt that a minimum one-week hospice rotation would be extremely beneficial, as it would give students the opportunity to have some hands-on experience. The limitation of this research is that it used self-report methods, it therefore measured a participant's perception of change and the lack in its ability to analyse actual behavioural change. One final important point highlighted by Carla et al.'s study is that the UCT postgraduate program is an elective program, so only doctors who choose to further their studies in palliative medicine receive this beneficial training. Due to an increasing burden of illness in SA, Carla et al. stated that palliative care needs to become compulsory in the curricula of undergraduate medical education, as is in keeping with WHO's guidelines which emphasises professional education. Carla et al. ended their article by stating the importance of SA universities committing to include palliative care in their education programs, to ensure that the patient's quality of life continues to improve too (43).

Drenth et al. (2018) article explored the role that the Hospice Palliative Care Association (HPCA) projects have played in the development of palliative care in SA (44). HPCA, together with the Diana Princess of Wales Memorial Fund provided bursaries to healthcare professionals, so that they could enrol in UCT's palliative medicine diploma or degree courses (44). At the time of the article being written, 384 postgraduate students from SA and other African countries had enrolled in the course, 350 of whom had completed their studies with a Diploma or a MPhil in palliative medicine. It added that in 2009, UCT agreed to open up the course to other disciplines, including nursing, social work, dietetics, physiotherapy, occupational therapy and aromatherapy (44). The article went on to say that UCT palliative alumni are employed in all of the South African Medical Schools and have had the opportunity to integrate palliative care at the undergraduate level (44). This is an exciting development, as Carla et al. emphasised the need to introduce palliative training at an undergraduate level (43).

Since 2000, UCT's programme has developed and changed, and the University of the Witwatersrand (Wits) and Stellenbosch University also offer palliative care training. The HPCA has continually developed a number of locally accredited programmes that have also been provided throughout SA (44). Palliative care is slowly starting to be a part of the training which doctors, as well as the multidisciplinary professionals, are receiving.

In May 2018, a group of South African doctors who trained in palliative medicine formed a non-profit organisation called the Association of Palliative Care Practitioners of South Africa (PALPRAC) (45). The PALPRAC was formed to create a peer support network for doctors practising in the palliative field, as many often work is isolation. Doctors are also able to get advice on how to manage difficult symptoms, and also discuss complex ethical issues. Their goal was to improve the access to quality palliative care, which as mentioned earlier has mainly been provided by the non-government sector in SA, and only in small pockets of the formal medical sector. The PALPRAC hope that this will change with the approval of the SA National Policy Framework and Strategy for Palliative care (45).

It will be interesting to discover from this study whether there is a difference in the perception and in the implementation of palliative care between doctors who received palliative care training during their undergraduate training, and those who did not, as well as whether there are currently more palliative services available in both private and in public hospitals in SA?

2.6 Provision of Palliative Care in SA: Public vs. Private Hospitals

2.6.1 Public Hospitals

With the approval of the SA National Policy Framework and Strategy for Palliative care by the National Health Council, Gwyther et al. (2018) realised that it was pertinent to reflect on the current initiatives that are in place in public hospitals in the Western Cape, to develop palliative care (46). Gwyther et al. in their article, “Palliative Care in the Western Cape’s public hospitals” describe current palliative care models available at tertiary, provincial and district hospital levels. In their article they summarise the development of palliative care teams in SA (46). The first hospital based palliative care team was established in the Charlotte Maxeke Johannesburg Academic Hospital in 2001. The success of this innovation led to further formation of smaller palliative care centres of excellence within the public health sector in Gauteng, namely Gauteng Centre of Excellence for Palliative Care at Chris Hani Baragwanath Academic Hospital in Soweto (established in 2001) and the N’Doro Project (established in 2003). The N’Doro Project provides specialist palliative care services, outreach visits to the Soweto community, provides training, conducts research and advocates for palliative care. A study of the N’Doro Project revealed that it successfully reduced hospital costs, in that there was a reduction in congestion and freed hospital beds for acute care patients (46).

Palliative care services were first introduced in the public health sector in the Western Cape in 2009 at the Victoria Hospital, which is a large district hospital in Cape Town. The palliative care program at the Victoria Hospital is called Abundant Life. In a similar manner as the N’Doro Project, the study revealed that patients who were enrolled in the Abundant Life program had fewer admissions to hospital, shorter stays in hospital, higher rates of supported home deaths and lower hospital costs in comparison to the control group (46).

Groote Schuur Hospital (GSH) is a large teaching hospital in Cape Town, and palliative care was introduced to the hospital in 2011 (46). GSH found that there was a need to improve the end-of life care of patients arriving in the emergency unit who were not expected to survive beyond 24 hours, so these were not seen as a priority for admission, given the pressure of bed shortages. GSH staff received training and mentorship from the ward, staff, St Luke’s hospice and the Hospice Palliative Care Association of SA (46).

Gwyther et al. also mentioned a research study conducted by Van Niekerk and Raubenheimer in 2013, which found that 20.3 percent of the patients in the medical wards had life-limiting illnesses, which would benefit from palliative care. Other studies also highlighted the need for a palliative care team, and these findings were used to motivate for a multidisciplinary palliative care team at GSH. The main objectives of the team is to ensure that a comprehensive palliative assessment is done, to assist with discharge planning, pain and symptom control, to provide psychosocial and spiritual support to both the patient and their family, link patients with community-based service and to follow-up telephonically, which includes bereavement calls (46).

There are also various partnerships being formed between district hospitals and hospices. For example, Stellenbosch and Knysna Provincial Hospitals have teamed up with their local hospices to provide palliative care services and develop palliative care plans for patients who are referred to them (46).

Gwyther at al.'s article has given a detailed outline of the current palliative care initiatives in the public sector. From the article it is clear that major strides have taken place in the South African public health setting, benefitting not only patients and their families, but the hospitals too. Can the same be said about the private health setting?

2.6.2 Private Hospitals

There was no evidence in the literature reviewed which suggests that any focus had been given to developing palliative care within the private hospital setting. Doctors and members of the multidisciplinary team may be advancing their palliative care skills individually, but whether palliative care is being offered as part of a patient's comprehensive care or is not being offered at all within the private settings is of concern.

There was however a study conducted by Hlahatsi et al. (2017), in eleven intensive care units in four private hospitals in Gauteng, in which a non-experimental, descriptive study was conducted to discover whether the needs of the significant others of critically ill patients were being met (47). The study highlighted how it has been found that if a patient's significant other needs are recognised and met, that it benefits the healing process of the patient too. Although this study did not discuss palliative care specifically, many of its recommendations made by the researchers, highlight palliative care principles. The recommendations that were linked closely to the WHO's definition and principles of palliative care were: education needs to be given to the medical staff to help them identify and address the needs of the family; open and honest communication needs to take place between the multidisciplinary team and the family, as decision making and goals of care often need to be decided by the family, as the patient may not be able to do so; and finally the spiritual needs of the patient and the family were often over looked. The study highlighted spiritual needs as equally important, especially in a country as diverse as SA (47). All these recommendations could be addressed by a palliative care team, as palliative care acknowledges the importance of offering a support system to the family and attends to their spiritual needs too (6).

The *National Patients' Rights Charter* (2008) states that, "everyone has the right to access health care services". Palliative care is included in this list as a service that all patients facing a life threatening or a terminal illness must receive (48). It will be interesting to discover what the current position in private hospitals is, in terms of accessibility to palliative care services.

The Lancet Commission on Palliative care and pain relief once again highlighted the huge burden that is caused by health-related suffering, which could be alleviated to a large degree by palliative care intervention and effective pain control (49). However, the findings of the Lancet commission also stated that middle to low income countries have severely limited access to both palliative care and pain control. Access to inexpensive and essential morphine, as well effective palliative care interventions, is not so much an issue of affordability, which is so often the case in health, but rather accessibility (49). It will therefore be important to further explore if the struggles to access adequate pan control and palliative care is a similar struggle in both private and public health setting in South Africa.

2.7 Conclusion

From the literature reviewed for this research, it has been noted by the various studies, that doctors do see the value of palliative care, but they still struggle to see the role that they can be playing, or when to initiate palliative care interventions. Research is starting to emerge in which it looks at the impact of early palliative care, introduced from diagnosis alongside curative interventions. Evidence from reviewed studies suggest that some of the benefits of early palliative care have been an overall improvement in the quality of life, less depression and a better understanding of one's diagnosis. Early introduction of palliative care may also increase the overall survival of patients, as was revealed in the study of NSCLC patients.

Doctors do however still struggle to have open and honest communication with patients, and this could be an ongoing barrier for palliative care being introduced to patients who are facing a life-threatening illness. The other challenge that became prominent in the literature reviewed is the training and the education that doctors receive. Although palliative care is being introduced now during a medical doctor's undergraduate training, the impact that this will have in the long-term on a doctor's perceptions and the provision of palliative care remains to be seen.

Education has been lacking in the past, and so doctors who qualified many years ago may still lack an understanding of what palliative care is, and how they can play a role in providing it to their patients. It is however exciting to see the growth of palliative care in the public sector, and hopefully this study will demonstrate development occurring in the private hospital settings too. Palliative care it seems is developing and growing in SA, and it will be interesting to see current perceptions and the provision of palliative care by doctors in the private hospital setting.

2.8 Rationale for the Study

Palliative care is one of the core components of providing patients with comprehensive care across their life span. It is every health care professional's ethical duty to provide this care when required, as stated in the World Health Assembly Resolution 67.19. However, the reality is that futile treatment is still being offered to patients, and difficult and honest conversations about a patient's prognosis, are often avoided, out of fear that a patient may "give up". Palliative care aims to maintain a patient's quality of life, from diagnosis to death, but this cannot be achieved if palliative care is not part of the continuum of care being offered to patients. At times palliative care is simply viewed as end-of-life care and is only introduced in the last 3 to 6 months of a patient's life. Some doctors feel that it's specialised palliative care doctors who can play a role but only when a patient can no longer be cured. The call now is for caring and curing to take place alongside each other, because every ill patient can benefit from palliative care.

With the current COVID-19 pandemic, healthcare professionals from various disciplines will be involved in the care of seriously ill patients who have COVID-19. Doctors will be faced with not only the challenge of managing their acute symptoms, they will need to play a role in alleviating distressing symptoms, by making use of good communication skills in order to ensure that patients receive compassionate and dignified care (45). Every patient needs good symptom control, emotional support and comfort, even when having curative interventions. Palliative care should be offered to patients and their families whenever there is need for it and all doctors should be equipped with the skills, that they need to provide this care. The current COVID-19 outbreak has shown this to be true.

The COVID-19 pandemic has also highlighted the many things the palliative care field does very well, but it also has offered an opportunity to reflect on the work that still needs to be done. Spiritual care has been identified as an area that is lacking, as the pandemic has revealed how ill-resourced and often too poorly staffed many hospitals are to provide the spiritual care that is needed to ensure whole person palliative care (50). Doctors need to become more aware of the role they need to be undertaking in assessing the spiritual needs and concerns of their patients. This is a skill that they will need to learn, so that they can advocate for the involvement of a Chaplin and other spiritual providers, or simply offer a non-judgemental listening ear, which is often all that is needed (50).

From experience and the literature reviewed, the researcher has come to realise that a doctor's perceptions of palliative care may be a key factor in determining the efficacy of palliative care provision at all levels of care. To expand on this, it is therefore crucial to explore a doctor's entrenched views with regard to how they perceive palliative care and whether patients within the private hospital setting are more or less likely to receive adequate access to effective palliative care provision.

It is from this background that this study seeks to explore the perceptions of doctors and their provision of palliative care in a private hospital setting. Furthermore, to understand to whom and how is palliative care provided for in the private hospital setting.

2.9 Research Question

What are doctor's current perceptions on palliative care and what role do they play in providing palliative care in a private health care setting?

2.10 Aim and Objectives

AIM: To explore the doctors' perceptions and experiences of palliative care and the role that they currently play in the provision thereof in a private hospital, in Gauteng.

OBJECTIVES:

1. To explore the doctors' experiences of pain and symptom management in palliative care.

2. To explore the doctors’ perceptions of palliative care, goals of care and teamwork in palliative care.
3. To explore the experiences of doctors’ provision of palliative care at the study hospital.

CHAPTER 3: METHODOLOGY

3.1 Introduction

This chapter explores the methodology and the design chosen by the researcher to ensure that a structured and comprehensive plan was put in place to conduct sound research that answers the research question. This chapter will discuss the study design chosen; the sampling method and the size; the step-by-step data collection plan, the tools that guided the process and the safe storage of the data collected. It will then discuss how the data was analysed, and the measures that were put in place to ensure that the research is trustworthy, credible and that all the necessary ethical considerations were put in place.

3.2 Study Design

A qualitative approach was chosen, as the focus of this research was to gain a deep understanding of the doctor's perceptions and the provision of palliative care at the selected private hospital in Gauteng, using a smaller number of participants than in quantitative research. A qualitative approach allowed for a lot more information to be collected and rich understanding of the topic was generated (51). This qualitative study used exploratory and descriptive research design. The exploratory arm of the design was used to encourage doctors to explore their current perceptions of palliative care, with the hope of gaining insight into the doctors' current beliefs and experiences of palliative care (52). The descriptive arm of the design looked at "how" and "why" doctors provide palliative care to their patients.

3.3 Study Site

The study was conducted in a Private Hospital in Gauteng, South Africa. It is an in-patient hospital with a capacity of 323 beds.

3.4 Inclusion Criteria

- All permanently practicing doctors at the study site.
- Available doctors during the period of conducting the study.

3.5 Exclusion Criteria

- Locum and visiting doctors.

- Doctors who were unavailable during the study period.
- Doctors who chose not to participate in the study.

3.6 Sampling Method

Convenience sampling was used for this study. A convenience sample is a type of non-probability sampling method where the sample is taken from a group who are easily accessible and who are willing to participate in the study (53). The convenience sampling method was suitable for this study as it enabled the researcher the opportunity to further explore personal observations made in the work setting from the participants who were familiar with the phenomenon being studied.

3.7 Sample Size

The sample size for this study was initially anticipated to be between 15 to 20 participants, or until data saturation was reached. The researcher interviewed fourteen participants when data saturation was reached. Data saturation is the point in the research when no new information is obtained, or no new themes emerge (54). Qualitative research usually has a small sample size, as the goal is to collect an extensive amount of verbal data based on individual experiences and perceptions of the participants (52).

3.8 Data Collection

3.8.1 Data collection tools

To ensure that the data collection tools developed for this study were trustworthy, the researcher sought expert guidance from the supervisor, conducted a rigorous literature review and engaged in discussions with palliative care colleagues. The knowledge and the information gained from these various resources was used in developing the interview guide used in the study. The following data collection tools were used in this study, namely: Face-to-face semi-structured interviews, interview guide, audio tape recorder and field notes.

Semi-structured interviews were used in order for the researcher to gain a detailed account of the participants' perceptions or beliefs of the particular study at hand (52). They were appropriate to be used in this study as there is a significant amount of objective knowledge about the phenomenon being investigated, but the subjective knowledge of that experience, which in this study is doctors' perceptions and the provision of palliative care in a private hospital, was lacking (55). Semi-structured interviews make use of open-ended, direct, verbal questions, in order to obtain detailed narratives from the participant and a set of pre-determined questions known as the interview guide or schedule was used to direct the interview (56). The interview guide (see Appendix A) was a vital tool that allowed the interviewer to engage with the participants in a way which ensured that the questions asked addressed the issue that the researcher was interested in. The questions guided the interview process, rather than dictated it. Semi-structured interviews are more flexible, they allowed the researcher to further explore interesting themes that emerged. It also allowed the participants to introduce an issue that the researcher had not even thought of, allowing the participants to decide the direction that the interview took, to be the expert in the study, and it also gave them an opportunity to tell their story (52).

An audiotape recorder was used to capture data. Making use of a tape recorder allowed for more accurate records to be made of the interview, without being distracted by taking notes. By making use of a tape recorder it also allowed the researcher to focus on how the interview was proceeding, and where to go next (52). Another advantage of recording the interview is, it allowed the researcher to observe any non-verbal communication that took place. Once the interviews were completed, the tape recordings could be transcribed verbatim. Field notes were also kept by the researcher. The field notes were short notes taken by the researcher to record observations, thoughts and reflections made during the study. The field notes were also used as a means of ensuring reflexivity took place (52).

3.8.2 Data collection process

The study was able to commence once approval was obtained from both the University of Cape Town's Human Research Ethics Committee (UCT HREC-see Appendix B) and permission was received from the private hospital where the research was conducted (appendix not included due to study site's request to remain confidential). In order to ensure the confidentiality of the participants, the private hospital where the study was conducted, may not be directly named in this research study.

(i) Study introduction and recruiting participants

The doctors were individually approached by the researcher, who introduced the study that was to be conducted to them. They were then invited to be a part of the study. Each doctor was provided with an information sheet (see Appendix C), which gave a more detailed outline of the study that the researcher planned to conduct. The doctors were then given an opportunity to read through the information sheet. The researcher then contacted the doctors telephonically a few days later, to see if they were willing to be part of the study or not. Any questions that may have arisen after reading the information sheet, were also answered.

(ii) Setting up interviews

If the doctor agreed to be part of the study, an appointment was set up to conduct the interview, at a time that best suited the doctor. All the participants in the study were interviewed in their own private offices. Before the interview started, the researcher ensured that distractions were prevented. Telephones were switched off, a ‘Do not disturb/knock-Interview in progress’ sign was displayed outside the door. Each participant also signed a consent form before the interview began (see Appendix D).

(iii) Conducting interviews

Interviews were conducted on a one-on-one basis, in a private office, and took 30 to 45 minutes each. Except for one interview, in which three doctors, working in the same medical practice, and having the same specialty, requested to be interviewed together. Due to time constraints of the doctors, the interview could not be reschedule to another day on which the three doctors could be interviewed individually. The researcher used her social work skills to ensure that each doctor was given an equal opportunity to answer the questions, in the group interview. Due to it being a group interview, it was important to encourage each participant to answer each question, and not simply leave one person to answer the questions. As the interview started, the researcher was concerned as it looked like one participant was going to dominate the interview, but by making use of further probing questions and prompts, all three participants did answer each question. The fact that they all studied at different Universities and are different ages, led them to want to discuss their individual experiences and their own perceptions of palliative care, as influenced by the training and education they had received.

Participants were asked if an audiotape recorder could be used in order to ensure accurate verbatim transcribing of the interviews after the interview process, so that detailed analysis could take place (57). One participant requested that notes be taken instead of a tape recording. Notes were made, and the interview was written up immediately after it was conducted, in order to ensure accuracy. The researcher felt that an accurate transcription of this interview was possible, in spite of not being able to record it, as making detailed process notes of the session with the patients, is part of the researcher's daily work.

Field notes were also kept in order to keep a written account of any thoughts that emerged while conducting the interviews, and to identify the ideas and themes that were emerging, while ensuring continued reflexivity (57).

The data was collected over three months.

3.8.3 Data storage and confidentiality

To ensure that individual privacy and confidentiality was protected, hardcopies of the transcripts and the field notes were locked in a cabinet, in the researchers own office, which is not shared with anybody else. The office is locked when not in use and the key is kept by the researcher at all times. Confidentiality was further maintained by keeping the signed consent forms in a separate sealed file. Data stored in electronic records, such as the audiotaped recording and transcribed interviews, were kept on a password-protected laptop, which only the researcher had access to, as well as knowledge of the password.

Audiotaped recordings will continue to be stored on a password protected laptop for a minimum of two years after the data is published, or six years if the data is not published, as outlined by the Health Professions Council of South Africa's (HPCSA) Guidelines for Good Practice in the Health Professions: General Ethical Guidelines for Health Researchers (58). Anonymity and confidentiality were further maintained by assigning a number to each participant for identification instead of using their real names, thus ensuring that their names remained anonymous. The hospital where the study was conducted has not been named, adding to the anonymity of the doctors.

3.9 Data Analysis

A grounded theory approach was observed throughout the study. Grounded theory is not based on an existing theory, but rather focuses on generating a theory based on the study of a social situation (57). A grounded theory is therefore an inductive process, in which hypothesis are developed from the ground up, and are not defined prior to the research (59). The inductive process allowed for categories to emerge from the data being collected (59).

After the first two interviews were conducted and transcribed, the researcher was immersed in the data. Data immersion means the data is read and re-read by the researcher in order to identify and to index themes and categories that were emerging in the first two interviews that were conducted. Such a process is referred to as constant comparison, which is to identify similarities and differences in each category and to be inclusive of all emerging new categories (57). At this stage the aim was not to reduce the data, but to rather include as many of the nuances in the data as possible (59). Before conducting the next batch of interviews, the researcher included a question that emerged as an area that could be further investigated, namely the training that the doctors received in palliative care. Palliative care training was said to be lacking by participants one and two in their interviews, and hence they were added to the interview guide. The second batch of four interviews were conducted, and data immersion took place again.

Once numerous categories started to emerge, coding commenced, whereby the researcher identified main ideas or thoughts brought out in the sentences or the paragraphs. The researcher started by making use of open coding, which involved the breaking down of data, in order to assess the similarities and the differences (52). This is done by making a line-by-line analysis of the data, in order to code the data in as many ways as possible. Highlighters were used in order to take note of the similarities (highlighted in the same colour) and any differences were initially underlined, in case there were similarities in interviews that were conducted at a later stage. During this time the researcher made memos about the theoretical ideas that emerged during the process of analysing the data (60). Then, the data needed to be put back together in new ways, by making connections between the categories and the sub-categories, known as axial coding.

Once a few categories started to emerge, selective coding needed to take place, which is the process of identifying core categories, and then systematically relating them to other categories, validating the relationships and also identifying categories that needed further refinement. Categories were then clustered together to form the first themes and sub-themes from the first six interviews (52). Once this process was completed with the first two batches of interviews, the next batch of four interviews were conducted and analysed as above. The researcher constantly moved between the three methods of coding (open, axial and selective coding). New themes that emerged were included in the existing list. The final batch of four interviews where then conducted and analysed in the same manner, and data saturation was reached, as no new information emerged from the interviews (61). When the data analysis was completed, there was a total of eight themes and twenty sub-themes.

3.10 Trustworthiness and Credibility

In order to conduct good qualitative research, one needs to ensure that the findings are trustworthy and credible (62). Trustworthiness, or the rigour of a study, is the degree of confidence in which one can say that the data collected, the interpretations made, and the methods used, ensures that a quality study is conducted (63). The interview guide that was used to collect the data in this study, made use of the literature reviewed, as well as the input of the supervisor and the colleagues working in the palliative field. This was to ensure that the interview guide would answer the research question, and also to ensure that if this interview guide was used in a different setting, that it may yield similar data. Interpretations made from the data analysis were also reviewed by the supervisor to ensure that accurate interpretations of the data were being made.

Credibility is whether the truth of the data or the participants' views, are accurately interpreted and represented by the researcher (62). This study made use of a strategy called triangulation, to ensure that credibility was achieved. Triangulation is when one makes use of multiple sources to draw conclusions (62). The researcher therefore made use of the interviews conducted, the observations made and the field notes kept, in order to continually reflect on the data collected, to ensure that any preconceived ideas held by the researcher did not influence the findings of the study. This process is called reflexivity.

Reflexivity is the continuous process of self-reflection that researchers engage in, in order to be aware of their thoughts, their actions, their assumptions and their perceptions (64). In other words, the researcher turns the lens back on themselves, in order to be aware of how their own position or their bias may influence the process of data collection and analysis (65). Reflexivity was an important principle to uphold, in order to ensure that an ethical study was conducted, since the researcher was conducting the study in their place of work. It was important for the researcher to be self-aware throughout the research process, to ensure that the researcher monitored the effects that their own values, their beliefs and the bias held going into the study, did not influence the findings of the study.

The researcher did not have an existing relationship with most of the doctors in the hospital, but she was aware of the fact that the doctors who she works directly with, may feel pressured to partake in the study. The researcher therefore ensured that if there was a previous working relationship with a potential participant, that this was not used to pressure the doctor into participating in the study, or manipulating the interview process so that the questions were answered in a particular way to validate the researcher's thoughts or ideas. The researcher endeavoured to remain objective during the interviews, to allow the participants voices to be heard, and asked open-ended questions that encouraged honest discussions around the research topic and avoided leading questions. The research also ensured a non-judgemental attitude was maintained during each interview, which is one of the core values of social work, ensuring that doctors perceptions and experiences of palliative care were not judged in any way during the interview process. Continuous self-reflection by the researcher allowed the participants the space to share their views, enhanced the accuracy of the findings, and ensured that the study remained credible and trustworthy.

3.11 Ethical Considerations

The study was able to commence once approval was obtained from the University of Cape Town's Human Research Ethics Committee (UCT HREC-See Appendix B) and permission was granted by the private hospital where the study was conducted. In order to ensure the confidentiality of the participants, the private hospital where the study was conducted has not been named. The participants in this study were doctors and they were not in a vulnerable position, as they were not ill or elderly. The study topic was less likely to be emotive and there was no anticipated distress, hence there was no inclusion of a distress protocol.

To ensure that ethically sound research was conducted, the following ethical principals were pursued: informed consent, voluntary participation, autonomy, confidentiality, privacy and anonymity. The researcher gained informed consent from the doctors, by ensuring that as eligible participants, that they were first provided with all the information regarding the study. It was important to note that involvement in the study was on a completely voluntary basis and that the participants could withdraw from the study at any time, if they so wished (autonomy). Confidentiality was also assured by letting eligible participants know that all the information received would be kept confidential and all interviews would be conducted in a safe and private space. Anonymity was also provided to the participants by assigning them with a study identity number, ensuring that responses could not be traced back to the participants.

CHAPTER 4: RESULTS

4.1 Introduction

This chapter presents the results collected from one-on-one semi-structured interviews conducted with the participants. The data collected was analysed, coded and then grouped into themes and sub-themes. The findings will be presented in a table form and then elaborated on thereafter.

4.2 Sample Demographics

Fourteen participants were interviewed at which point data saturation was reached, as no new themes and sub-themes emerged. The participants were made up of two Oncologists, four Physicians, two General Surgeons, one Cardiothoracic Surgeon, one Specialist Surgeon, one Hematologist, one Gynae-oncologist, one Intensivist and one General Practitioner. Nine of the participants were male and five were female.

4.3 Table of Theme and Sub-Themes

Themes	**Sub-themes**
1. Improving Quality of Life	1.1 Symptom relief 1.2 Providing comfort and maintaining dignity 1.3 No further active treatment available 1.4 Associated with End-of-life
2. Palliative Care is a Role for Oncologists	2.1 Most doctors provide palliative care 2.2 Focus remains on curing the patient 2.3 Training of doctors in palliative care should receive greater attention
3. Late Referrals to Palliative Care	
4. Views on WHO Analgesic Pain Ladder	4.1 Patients seen often require strong opioids 4.2 Tool seen as out-dated
5. Morphine is a Controversial means of Pain Control	5.1 An effective method of pain control 5.2 Not a drug of choice for pain control 5.3 Explaining side-effects
6. Team Approach	6.1 Palliative care involves a multidisciplinary team 6.2 Specialised palliative care team
7. Family Involvement	7.1 Open and honest communication with families 7.2 Managing family’s expectations 7.3 Doctor’s time constraints
8. Providing Spiritual Care	8.1 Doctor’s feel unequipped to address a patient’s spiritual pain 8.2 Not the role of a doctor to address spiritual pain 8.3 South Africa has diverse spiritual practices

4.4 Theme 1: Improving Quality of Life

Most of the participants mentioned that improving the patient’s quality of life is the main goal of palliative care, including the following:

4.4.1 Symptom relief

Most participants mentioned that palliative care focuses on relieving symptoms and alleviating pain.

"Palliative care is just, taking care of the symptoms of a patient". (P 001)

"To stay with the patient's needs, which is usually, pain free, symptom free and the best quality of life, for as long as they can, and with what they know". (P 002)

"To alleviate pain and give someone a dignified death". (P 013)

One participant stated that all doctors do not particularly focus on relieving symptoms at the start of the illness trajectory.

"It's the non-primary definitive curative therapy that is being implemented, it's pain control, it's nausea control, umm and I think that all of us do not do that from the start ..." (P 008)

4.4.2 Providing comfort and maintaining dignity

Some participants highlighted how both these values are at the core of palliative care and should be constantly observed while providing care, at the end of life stage and at death.

"To Keep the patients comfortable". (P 001)

"... we are to make that as comfortable as possible for the patient". (P 003)

"So, the main goal is to make the patients comfortable, to maintain the patient's dignity and privacy ..." (P 011)

"To keep the patient comfortable and improve their quality of life". (P 012)

"... an honourable death". (P 005)

"To make their final days of the patient's life as comfortable and dignified as possible".

(P 007)

"Really end-of-life care, but sort of the, you know, the dignity and respects of it". (P 009)

4.4.3 No further active treatment available

Most of the participants explained that the main goal of palliative care was to provide supportive care when no further active treatment can be offered to the patients.

> *"When there is no further active treatment for the condition of their disease".* (P 001)

> *"Support of a patient, with no further active, therapeutic intervention, but doesn't mean no more supportive intervention".* (P 003)

Some of the participants shared how doctors tell patients why they should be on palliative care.

> *"You know you are on the palliative care now, because we can't treat you".* (P 002) quoting what doctors tell the patients they refer to her.

> "*They are generally patients you can do nothing for*". (P 012)

4.4.4 Associated with end-of-life

Most of the participants equated providing palliative care with end of life care.

> *"We are looking at the terminal phase of life, or end-of-life phase".* (P 003)

> *"To allow the patient to, ahhh, to pass, the patient and the family, to experience minimal trauma as possible, due to the inevitable passing of the patient, and provide, like I said, said, end-of-life care".* (P 006)

> *"... it's about quality of life, of what's left of life"*. (P 009)

> *"… but for me it is a way of making the last part of the road a lot easier to walk".* (P 013)

4.5 Theme 2: Palliative Care is a Role for Oncologists

Many of the participants mentioned that it is Oncologists who should provide palliative care.

> *"Oncologists can play a big role in their palliative care".* (P 012)

> *"I'm assuming that you guys (referring to the Oncology team) are managing a large, a large part of it".* (P 009)

> *"... most patients end up with Oncologists because they are already managing those patients". (*P 010)

4.5.1 Most doctors provide palliative care

A few of the participants mentioned that most doctors play an active part in providing palliative care, but they do not necessarily label it as such, because they do not feel that their role is palliation, or that their intervention is palliative.

> *"So, when we say palliative, it doesn't mean there is nothing much we can do, there is still surgical interventions we can do".* (P 003)

> *"And they need an ileostomy, it's just a palliative ileostomy, it's usually in the ovarian cancer patients".* (P 010)

> *"I will do a palliative hysterectomy to try and stop the bleeding, make life a bit simpler ... you know at some stage you're going to have to go for palliation, where we care rather than cure".* (P 013)

4.5.2 Focus remains on curing the patient

A few of the participants mentioned that their role was to seek a cure for a patient and if this was not possible, patients would be referred on for palliation.

> *"My job is to Cure…have to seek adequate palliative support or supportive care for the patient".* (P 003)

> *"I do not think that (referring to palliative care) is my role as a Physician".* (P 012)

One participant added that their focus remains on a cure, and only once they have patients who die, do they as a doctor begin to learn how to deal with the fact that they cannot cure all patients.

> *"... the focus remains on curing a patient, and once you start having patients that die, you begin to learn how to deal with it".* (P 012)

4.5.3 Training of doctors in palliative care should receive greater attention

Many of the participants stated how they did not receive palliative care training, and that this was needed.

> *"Doctors are not trained to palliate patients".* (P 001)

"... because they are scared to look after the patient. It's just a ... and that is GP's and Specialists, they are not trained to look after really ill patients, that need palliation and that's why they refer them to us, because we are more trained in doing it". (P 001)

> *"I think unfortunately I have to admit that we don't do it enough, it needs more attention, it needs to be a greater priority ... I think it needs to be; it needs to receive greater attention in the academic sector. Conferences need to offer palliative care courses more ... Umm, but it needs to start at medical school".* (P 008)

> *"No one trains you on how to manage a dying patient".* (P 012)

4.6 Theme 3: Late Referrals to Palliative Care

A few of the participants highlighted how patients are referred too late for palliative care when they are no longer responding to treatment.

> *"... only really start focusing heavily on palliative care when we get to the point where the patient is no longer responding to treatment".* (P 008)

> *"I think that sometimes we are referring patients too late for palliative care, you know to the palliative doctors. I think once the patient is definitely metastatic, even though they are on palliative treatment, they should already start seeing their palliative doctors…".* (P 014)

4.7 Theme 4: Views on WHO Analgesic Pain Ladder

Most of the participants were familiar with the analgesic step ladder and were using it, while only two were not familiar with it.

4.7.1 Patients seen often require strong opioids

Most of the participants agreed that by the time patients are referred for palliative care their pain is so severe that they require strong opioids, there is no time to even consider weak and mild ones.

> *"By the time we get the patients they are actually, their pain, umm is past the Panado stage and things like that, so we mostly use either radiation or the morphine for umm pain control, so its seldom that we really start with the, at the bottom of the ladder and then the second phase or then the, to the morphine, so most of the time people have got severe pain and so we don't normally follow that WHO ladder".* (P 001)

> *"… but mainly you know I think in Oncology, we see patient's you know, the person that they see us, they are in so much pain that you actually start on top of the ladder".* (P 014)

One participant however indicated that because the patient population seen are elderly, they do not often consider strong opioids.

> *"If you look at the general population of patients that I see, they are more often than not, elderly patients. So, age is a concern when you look at the pain ladder. So, I tend to stick to the lower analgesics".* (P 012)

4.7.2 Tool seen as out-dated

Many of the participants mentioned that they do not necessarily use this tool to treat pain as there are various pain management tools that they can use.

> *"No, we don't refer to it. If the patient doesn't experience pain relief, then we go up to the next level, and the next level. There're all the other pain classification scores as well. We look at the De Beer's scores, isn't it for multiple things, but we don't really use it, we use it according to the pain …".* (P 004)

> *"We use a multimodal analgesia approach …"* (P 011)

One participant mentioned that the tool is out-dated and with advanced science and technology, there can be better ways of managing pain.

> *"To be honest with you, I don't really think it works … I think it's a bit out-dated. I think it needs revision … I think with our science and technology today, we can probably find a better way of assessing pain".* (P 010)

4.8 Theme 5: Morphine is a Controversial means of Pain Control

When discussing the use of morphine, it was evident that the participants were either for or against the use of morphine.

4.8.1 An effective method of pain control

Half of the participants used morphine often and thought that it was a very effective method of pain control.

"... usually I cut straight to the chase and go straight to morphine". (P 003)

"Morphine is one of those agents that is part and parcel of our arsenal, to, ahhh, address pain on a day-to-day basis". (P 011)

"... that's the only thing relieving some of our patient's pain. Especially if you've got a patient with bone metastasis, umm, you know, they are really in extreme pain, you know and, mostly to, to get their pain under control, it's better starting them straight away on morphine IV, to get their pain controlled". (P 014)

4.8.2 Not a drug of choice for pain control

The other half of the participants did not like to use morphine for a variety of reasons, ranging from the effect that it has on a patient's quality of life, to the concerns around using it for their elderly patients. Some doctors simply stated that they did not like morphine and do not prescribe it often.

"The opioids do have a significant impact on the patient's quality of life, and what you are wanting to keep is quality of life". (P 003)

"We prefer not to use opioids in our elderly patients as well, but for palliative cases, yes, opioids". (P 004)

"I must be honest; I am not a fan of morphine". (P 008)

"... So, I definitely don't like morphine ... morphine is such a dirty drug, and I now it is prescribed often, but it dissociates you from pain ... often I don't think it treats your pain".

(P 009)

"The problem with morphine is, particularly in the ICU and our pain, and you see it upstairs (ICU), nobody ever gives enough ... (P 009)

4.8.3 Explaining the side-effects

Although some of the participants discussed the side-effects of morphine, many only highlighted a few side-effects or discussed it with the patient's family, and not the patients.

"*Yes, I explain to the family what they might expect, not what they are going to expect. And I always, well I try, and if I say that, if they experience nausea, what to do. Cut back on a ml or not only tell them the side-effects but tell them what we can do".* (P 002)

> *"Shallow breathing, but I mean if it is palliative care, that's to ease the suffering, and you tell them the benefits as well, in which the patient doesn't actually struggle that breath, breathing, it sort of eases that sort of psychological burden as well".* (P 004)

> *"I often tell the, the family what to expect, more than the, the patients in that. Look some, a lot of the time my patients are on ventilated, or they are not capable of always making that decision. So that's part of it, so it's a family, a family-based consultation more than anything else".* (P 009)

> *"I usually tell them, just things like, say for instance, dizziness and constipation, umm, and sometimes nausea, but I don't go in to so many details with them, regarding the morphine, and I must admit, there are some patients that I did not tell them, when I gave it to them".* (P 014)

One participant felt that the morphine doses she used are so low that the only side-effects would be nausea and vomiting, and therefore she made sure that the medication was written up for these side-effects, and did not discuss them with the patient.

> *"Not really. Because I generally give low doses, in which the main side effects are nauseas and vomiting, and I always make sure that medication is prescribed to address those symptoms".* (P 012)

4.9 Theme 6: Team Approach

All of the participants involved in the study acknowledged that palliative care requires a team approach. Many participants also highlighted that there were currently no palliative care teams in place in the hospital. Some of the participants still felt that the Oncology team addresses the palliative care needs of the patients.

4.9.1 Palliative care involves a multidisciplinary team

All the doctors in the study acknowledged the need for a team approach when working with a palliative patient.

> *"I don't think any professional person can do palliative care alone. It's not an alone thing, no".* (P 002)

> *"I really feel that every doctor, every specialist, every allied health care professional, has a role to play in the palliative care of a patient ...".* (P 008)

> *"... So, once we identify that a patient is for palliation, we do involve the Psychologists, the Psychiatrist, the social worker, umm and then of course make sure that everyone on the intervention team, whether it be the nursing team, the physiotherapist, occupational therapist, speech therapist, are all aware that there is umm no escalation of therapy".* (P 014)

4.9.2 Specialised palliative care team

A few of the participants added that they would ideally want a specialist palliative care team in the hospital, who they could refer their patients to.

> *"... there's no structure, like you know, in place for us to access palliative care ... If we had a palliative care team, which we actually proposed four years ago, when we were discussing end-of-life care in the ICU, is to have a team to discuss when is palliative care required, when is futility of care ... very important for that, to formalise it".* (P 004)

> *"Unfortunately, we don't have a specialist palliative care team available at the institution, umm, should there have been such a qualified specialist or sub-specialist, I would most definitely often involve them...".* (P 011)

One participant mentioned a network of specialists that they are currently building.

> *"So, currently we're in the fortunate position we are trying to build up a network of doctors working and support staff working together".*

4.10 Theme 7: Family Involvement

Many of the participants highlighted the need for the patient's families to receive open and honest communication, and also to actively manage the family members expectations. However, many also highlighted the doctors challenge of time constraints, that hindered the process of keeping families well informed.

4.10.1 Open and honest communication with families

A few of the participants mentioned the importance of ensuring open and honest communication with the patient's family.

"Often palliative care is about the family crying with the patient, and not behind their backs. You know so, if the family's well informed like the patient, it's a, it's a team thing within the family and the community ... (P 002)

"... So, first of all, it's communication, so patient's family needs to know what's going on". (P 003)

"... I think patients always and family members always need to hear from a doctor". (P 004)

"... communication with the patient's family is of paramount importance". (P 010)

4.10.2 Managing family's expectations

Many of the participants acknowledged the role that they need to play in managing the expectations of the patient's family.

"... to ease the patients suffering, so they don't linger on, and just to co-ordinate that with the family and make sure they know what to expect". (P 005)

"... I think our role at the end is not so much with regards to the patient who is willing to accept, it's more about counselling the family members about what to expect, and their expectations there". (P 004)

"I think a big thing is to manage expectations, and this is by making the goals of treatment clear". (P 012)

4.10.3 Time constraints

Although the participants did feel that a patient's family needs to be well informed and have their expectations managed, some of the participants also noted that the lack of time they had, made it difficult to address the information needs of the families.

"*A doctor working a twelve-hour day, does not have the time to counsel like twelve family members for an hour and a half, it's just not possible"*. (P 006)

"We do rely heavily on the social workers to deal with the families, just because of time constraints". (P 008)

4.11 Theme 8: Providing Spiritual Care

Most of the participants made it clear either verbally or non-verbally that the question regarding whether they ever picked-up a patient who was in spiritual distress/pain, followed by the question of whether they felt that they had a role as a doctor in their patient's spiritual care, was both interesting and unexpected. Most of the participants felt that they were not qualified to deal with a patient's spiritual distress, but they also acknowledged that it had come up at times.

4.11.1 Doctors not equipped

Most of the participants in the study felt that they were not equipped to address the spiritual pain of a patient.

"... maybe some guidance, in a way, but I'm not really equipped, I'm not a counsellor, I'm not a Pastor, so I will then ask them to go and see someone that is actually equipped to deal with the spiritual side of things as well". (P 001)

> *"... patients tend not to confide that (spiritual pain) in me, or not express that, and if they did, I would probably feel ill-equipped to deal with it".* (P 009)

4.11.2 Not the role of a doctor

Most of the participants in the study felt quite strongly that a doctor did not have a role to play in addressing the spiritual pain of a patient.

> *"I don't think it's appropriate, I think you're there to give the physical information, and obviously from a human point of view your connected that point of view, but I don't think it's appropriate to be delving in to the spiritual and religious aspects of a patient".* (P 006)
>
> *"Much safer to stay clear".* (P 011)

One participant did not feel that doctors had a role to play in addressing a patient's spiritual pain, but added that if a patient did bring it up, that it is hard as a human to not support them, and engage in the conversation.

> *"As a surgeon, probably you don't have a role to play, as a person, a human dealing with another human, it's very difficult, if they can engage on that level with you, for you not to engage at that level".* (P 003)

4.11.3 Diversity of spiritual practices

Many of the participants felt that due to the large number of spiritual beliefs and practices in SA, it would be impossible to address the spiritual pain of a patient, unless they share your own spiritual beliefs.

> *"... but ones got to be very careful of imposing your own spirituality and your own religious beliefs on patients".* (P 007)
>
> *"... if you as an individual is of one denomination, it is sometimes not fully possible for one to understand fully the interpretation of a patient or a family member, in the light of their own religious convictions, and then the other problem also comes ... that should you attempt to express or sympathise along the lines of a specific religion, that, team members on your team, that's of different conviction may feel that you are undermining their religion".* (P 011)

One participant added that even if the patient did share one's spiritual beliefs, you may still offend a member of the multidisciplinary team, if they had a different spiritual belief, so he felt that it was an area to be avoided completely.

> "*In South Africa there are so many cultures, and so many religions, and so many different ways of practising that culture or religion. For example: Christians, there are so many different types of Christians, and the way they interpret or act out their faith is different. So how can I as a Doctor play a role, because even if we have the same religion, we may perceive it differently ... So, I do not think I could play a role in a patients spiritual care".* (P 012)

4.12 Generated Theory

Doctors still have a limited understanding of palliative care and are not yet equipped with all the skills needed to provide palliative care to the vulnerable patients and families that could benefit from it. The lack of a formalised interdisciplinary palliative care team also prevents a patient's total pain being addressed, preventing holistic care from taking place. In order to increase the accessibility of palliative care to all patients in South Africa requires doctors at undergraduate and postgraduate levels to receive standardised palliative care training to equip them with necessary knowledge and skills to include palliative care as part of the comprehensive care they provide to patients.

CHAPTER 5: DISCUSSION

5.1 Introduction

This chapter will discuss the findings of the study and explore how the perceptions and the current provision of palliative care by the participants in this study are in keeping with the current literature, or if they differ. It will specifically explore the findings of the study in terms of palliative care still *being viewed as end-of-life care,* palliative care services *being confined to malignant diseases*, how a patient's quality-of-life is currently *addressed by doctors*, and finally the lack of focus on *spiritual care.*

5.2 Palliative Care Viewed as End-of-Life Care

The study findings revealed that, although palliative care was seen as an important intervention, it was still mainly perceived to be end-of-life care. This is in keeping with Hanratty et al.'s (2006) study, in which palliative care was also seen as end-of-life care, when treatment shifted from treating the patient, to simply keeping them comfortable (5). In this study it was clear that doctors continue to view palliative care as end-of-life care. Patients are therefore referred to palliative care when the patient is no longer responding to the active treatment being provided. This is too late, as it prevents the patient from building a relationship with the palliative doctor and the team and benefitting from the overall improvement in quality-of-life that palliative care provides.

Rodriguez et al.'s (2007) study looked at how palliative care origins are very much rooted in hospice, where historically the patients were at the end-of-life stage and were typically cancer patients. This has resulted in the terms "palliative care", "hospice care", "end-of-life care" and "terminal care" being used interchangeably (4). This study found the same to be true, as palliative care and end-of-life care were seen as the same thing. This leads to palliative care being under-utilised (4). In this study, palliative care was viewed as the last resort of care, when no more active treatment can be offered. It was not viewed as part of the continuum of care that can be offered to all patients who have a life-threatening illness.

The findings of this study highlight the need to change the existing perceptions of palliative care as mentioned above. Jecker and Schneiderman's (1995) study recommended that cure and care operate alongside one another, as all patients will benefit from a total pain approach, even when receiving treatment that may result in a cure (37).

Most of the participants in this study articulated that palliative care was about quality of life, dignity and addressing the patient's distressing symptoms and facilitating good death. If palliative care is only introduced in the end-of-life phase of a patient's care, then it will not really be possible to improve the patient's quality of life and provide good symptom control. This is especially true for patients with life-limiting illnesses other than cancer, such as congestive heart failure, which does not have a predictable terminal phase or a progressive decline. A patient may die suddenly without ever having the benefits of palliative care interventions that encourages a good quality of life by ensuring the relief of distressing symptoms and addressing the psychosocial needs of the patient and their family (4).

5.3 Palliative Care Confined to Malignant Disease

The findings of this study have again revealed that palliative care is often seen as an intervention for cancer patients exclusively. Most of the participants in this study viewed palliative care as an intervention for cancer patients and the role of the Oncologist. However, palliative care should be an integral part of the management of any patient facing a life threatening or chronic debilitating illness, this was also stated by Krau (4), Gore et al. (66) and in WHO's definition of palliative care (6). By it being viewed mainly as an intervention for cancer patients, it prevents other patient population groups from accessing this beneficial intervention. It also results in doctors from other specialties not seeing palliative care as an intervention in which they have a role to play, and therefore they are not actively providing this essential service to their patients.

The findings of this study are in keeping with previous studies that have also identified that palliative care is often still seen as an intervention that is introduced to cancer patients exclusively. Gore and Greenstone's (2000) study compared the care provided to a COPD patient versus a lung cancer patient to highlight the importance of also providing palliative care interventions to all patients diagnosed with various life-threatening illnesses other than cancer. Their study specifically explored the provision of palliative care to these two patient populations and their overall quality of life. The study concluded that end-stage COPD patients had a significantly impaired quality of life and that they struggled emotionally. Although COPD patients' needs were similar to the needs of lung cancer patients, COPD patients' needs were often not recognised and therefore were never addressed or met, whereas the lung cancer patients had access to specialised palliative care services quite early in the trajectory of their illness (66).

The NPFSPC, which was developed after the World Health Assembly Resolution 69.17, requested all member states to develop policies that would strengthen palliative care services, has also acknowledged how palliative care was historically a service for patients with advanced cancers nearing the end-of-life stage. Although the services expanded to include HIV/AIDS patients, the SA Minster of Health in 2017, Dr Motsoaledi, recognised the need to ensure the equitable access to palliative services for a range of communicable and non-communicable diseases (2). This policy again highlights the need for all doctors to provide palliative care services to patients, both children and adults, who are facing a life-threatening illness. Despite the NPFSPC, the finding of this study again showed that palliative care services are not accessible to all patients, as it is still being viewed as a service provided exclusively to cancer patients.

The importance of accessible palliative care services has especially been seen during the COVID-19 outbreak, which WHO declared to be a pandemic on 11 March 2020 (67). Palliative care is a vital component of health care during a pandemic, as it ensures symptom control, psychological support and guides the difficult decision-making process (67). Borasio et al. stated that every COVID-19 patient should have access to palliative care, and added that it was an ethical imperative for all patients who are likely to die from COVID-19 to receive high-quality palliative care, due to the high symptom burden of dyspnea and anxiety (68). However, Powell and Silveira (2020) pointed out that the global shortage of palliative care specialists, and the increasing numbers of COVID-19 patients, makes this an impossible goal to achieve (69). The current COVID-19 pandemic has again highlighted the importance for all doctors to have a basic understanding of palliative care intervention, and that active treatment often needs to take place alongside palliative care (38). Yet many SA doctors still have very little training in palliative care as shown in this study whereby 57 percent of participants never received any formal palliative care training.

5.4 Palliative Care Training of Doctors in SA

In this current study it was clear that there was still a lack of palliative care training amongst doctors in South Africa. Just over half of the participants in this study received no palliative care training during their undergraduate or specialised training as a doctor, this is in keeping with the literature reviewed for this study. Gwyther et al. discussed the development of palliative care training, which only really started in 2000 in SA, at a post-graduate level at UCT (42).

Carla et al.'s article in 2011 evaluated the program being offered at UCT and noted the fact that the course was an elective post-graduate course. This article went on to identify the need for palliative care to become compulsory in the curricula of undergraduate medical training in all SA universities (43). There have however been developments in the training of palliative care in medical schools since this article was written.

Drenth et al.'s (2018) article looked at the development of palliative care in SA and noted how the UCT post-graduate program had trained doctors who were employed in various medical schools in SA. This has allowed for palliative care to be integrated into the undergraduate level at various medical schools in SA (44). The NPFSPC also stated that palliative care is now included in the undergraduate curricula of medical students at UCT and at Wits (3). Stellenbosch has also started to include palliative care training. Although this is a very encouraging development, there is still a lack of uniformity in content and in the quantity of palliative care being taught (2).

The findings of this study reflected the steady increase in palliative care training in SA Universities, as a few of the more newly qualified participants in this study did receive palliative care training. Training received at medical schools during undergraduate level ranged from 2 to 6 weeks. The training usually focused on end-of-life care and was offered during medical students' family medicine training, or as a two-week rotational placement at a hospice. The content of the training usually focused on pain control, and not the psychological impact of having a life-threatening illness or how to break bad news. However, what is an encouraging sign of growth in this area, is that one of the most newly qualified participants in the study had done a six-week rotation at the Gauteng Centre of Excellence for Palliative Care at the Chris Hani Baragwanath Hospital.

The formation of the Palliative Care Group of Medical Practitioners (PALPRAC) in 2018 was also a positive development, as it is the first peer support group for doctors practicing in palliative medicine and it also aims to improve the access to palliative care services in SA (45).

There seems to be steady growth in the training of doctors in palliative care, which was also seen in this study, as there were at least a few participants who did receive some palliative care training. As pointed out in the NPFSPC, and mentioned earlier, standardisation of this training and the content of palliative care being taught differs. The fact that, in this study, most participants, including some of those who had received some palliative care training, still viewed palliative care as an end-of-life intervention. This highlights the need for ongoing advocacy for the standardised training of doctors in palliative care at undergraduate and postgraduate levels.

5.5 Improving a Patient's Quality of Life

When discussing what palliative care is, most of the participants in this study knew that palliative care aimed at improving a patient's quality of life by ensuring that a patient is pain free. This is a very important role that doctors can play in palliative care, but who and how to get a patient to be pain free varied. The findings of this study support the various articles that have explored the differing views on WHO's analgesic pain ladder, as well as the use of morphine. Half of the participants in this study felt that morphine was an invaluable drug, and the other half of the participants did not like to use morphine at all, one participant went as far as to say that morphine was a *"dirty drug"*.

5.5.1 Pain control

In this study, most of the participants were familiar with WHO's analgesic pain control ladder, however the findings of the study revealed that participants did not use it, and the few that said they used it, added that the pain was often so severe that they skipped the first two steps and went straight to using morphine. WHO's analgesic ladder was also seen as outdated. Some participants felt that there were newer and better pain models that they could, and do, use. These findings are in keeping with studies conducted by Maltoni et al. (2005) (70) and Raffa and Pergolizzi (2013) (71) in which they also questioned the validity of WHO's analgesic pain ladder, which was first introduced in 1987.

Maltoni et al.'s study aimed at looking at whether moving directly from step I to step III of the WHO analgesic ladder, was more effective than the traditional three-step ladder. Step I of the ladder is non-steroidal anti-inflammatory drugs (NSAIDs) with or without adjuvants. Step II is weak opioids for mild to moderate pain with or without NSAIDs and adjuvants. Step III is strong opioids for moderate to severe pain with or without NSAIDs and adjuvants. The findings of Maltoni et al.'s study (54 patients) showed improvement in a patient's pain scales but added that side-effects were not always well addressed (70). Similar findings were made in this current study, as some of the participants also voiced how they skipped step II of the ladder, as patients were in so much pain, and needed a strong opioid, and so the participants felt that they would more effectively address the pain of the patient by going straight to step III, as suggested by Maltoni et al. (70).

Some of the participants in this study also felt that, with the improvements in science and technology, one could find better ways of assessing and treating a patient's pain. This is in keeping with the concerns raised in Raffa and Pergolizzi's article, which explored the advancements in our understanding of pain anatomy and physiology, as well as an increase in the types of pain medication available. They concluded that this called for changes to be made in the way that pain is addressed. They therefore suggested that WHO's pain ladder needed to be updated and modified, but still maintain its simplicity, intent and generality (71).

Despite the concerns raised by some of the participants in this study, and many stating that they did not use WHO's analgesic ladder, when discussing their pain management process further, many did use a step-up process. Although they may not all use WHO's analgesic ladder exactly as it was originally developed, many participants did acknowledge that it did guide their pain management thought process, and many spoke of starting with something weak and moving up from there. The findings of this study suggest that pain control remains challenging, and this is further complicated by the varied views of doctors and the perception of morphine.

Morphine was prescribed by half of the participants in this study on almost a daily basis. The participants who found morphine to be a very effective drug suggested that they used it mostly with patients in the end-of-life stage, and one participant even felt that it could help expedite the suffering and the dying process. Yet extensive literature shows that morphine is a drug that can be used for pain control for patients who may not be dying but are still in need of good pain control. Yet patients experiencing a lot of pain may not be given strong opioids due to the fears and myths around medication such as morphine. This was found to be the case in this current study, as a few of the participants were reluctant to prescribe morphine for their elderly patients. Some participants also had concerns around a patient's quality of life being negatively impacted due to the use of morphine, as they felt that it would cause sedation, nausea, vomiting, constipation and respiratory depression. Despite SA being praised for declaring morphine an essential drug (24), it was clear in this study that some of the participants did not view morphine in the same positive light.

The participants negative views of morphine, some of which are myths, have been connected to morphine for a long time, and various articles have tried to highlight the facts vs the myths. KHOO (2003) wrote an article on the myths and the facts about palliative care (72). KHOO specifically discussed how morphine, if used correctly, effectively addresses a patient's pain and other physical symptoms when looking at the total pain of a patient, without causing psychological dependency or respiratory depression. He added that a patient's pain needs to be continually assessed and adjusted, as morphine has no ceiling dose, and the right dose for a patient, is the one that controls the patient's pain, and has the fewest side-effects (72). The overall outcome of morphine is usually a better quality of life for the patient.

The fears mentioned by some of the participants in this study regarding the prescribing of morphine are often based on myths, and the concern therefore is whether the quality of life of the patient is being negatively impacted on due to uncontrolled pain. All palliative patients, whether young or old, should be given the opportunity to be pain free and have a good quality of life. However, with the myths around morphine persisting and misunderstanding on how morphine is used, which were highlighted again in this study, patients may not all be given the opportunity to make use of morphine, to see if their overall quality of life can be improved, and this is concerning. This is in keeping with the findings of the literature reviewed, as Rabow et al. found that primary health care providers prescribed opiates in only 8 percent of patients diagnosed with cancer, COPD or congestive heart disease (38, 40).

Pain impacts not only on a patient's physical well-being, but also on their emotional and spiritual well-being. Providing good physical pain control is possibly one of the most important roles that a doctor can play when providing palliative care. Poor pain relief continues to be the reality for many patients. It is therefore important for doctors to address the total pain of a patient; otherwise optimal pain relief will not be possible (73).

5.5.2 Teamwork, communication and the family

All the participants in this current study acknowledged the need for members of the multidisciplinary team to be involved in addressing the needs of a patient and their family. However, the findings highlighted the varied views and the current use of a team approach when it comes to a palliative patient's, as well as barriers. Two important barriers were highlighted in the study. First, the need for a formalised palliative care team, which was suggested at this study site four years ago but never materialised. Some of the participants hoped that this current study may be a catalyst towards putting a team in place. A second barrier was the belief by many of the participants that it was the job of the Oncologists, and their team, to address the needs of a palliative patient, a view that confines palliative care to an approach for cancer patients, as previously discussed. It also confines palliative care to the role of a few specialised palliative doctors and team members, where in fact all doctors can play a role in providing their patients with palliative care. While a palliative care team may provide more specialised services, it cannot simply be a handing over of patients to the palliative care team, leaving a patient feeling abandoned.

WHO's definition of palliative care states that it is a team approach (15). When a patient is facing a life-threatening illness, they are confronted with a number of challenges, as are their family members. They face physical distress, may lack coping skills, have a number of emotional struggles, or have unanswered spiritual concerns, and all of this impacts their quality of life (74). A team approach is needed to address the varied needs of a palliative patient and their family, and this has been acknowledged by Crawford and Price (16), Hermse and Ten Have (17) and Devi (74).

A patient's palliative care needs are best addressed by a multi-disciplinary team approach, but the team must provide integrated services to the patient and their family, in which their needs are addressed seamlessly across the health and social care providers, and by the different disciplines. In order for this to occur, palliative care training needs to become a priority (75). The recommendation has therefore been made to introduce mandatory palliative care training for all undergraduate health, medical and social work students (75). By ensuring that both doctors and members of the multi-disciplinary team have a basic knowledge and understanding of palliative care, it will make palliative care more accessible early on in the diagnosis of a life-threatening illness, and also at all levels of health care. A palliative care specialist could be part of the team, to assist with the more challenging palliative needs of a patient. This would also ensure that patients are not simply referred to a different team, or a new doctor when they are labelled for "palliative care", but would be able to build a relationship with their treatment team from the beginning, with different members of the team playing a bigger or lesser role as the illness progresses.

As it currently stands, there is no formalised team approach in the hospital where this study was conducted to address the needs of palliative patients, except for the cancer patients. Although most of the participants in this study stated that they referred patients to allied workers and their families to social workers, psychologists, trauma support and religious leaders, only two of the participants spoke of working as a team to address the needs of a patient and their family. A team approach with open communication between the team members would be more beneficial to the patient and their families, as opposed to members of the multidisciplinary team working independently, which often leads one to focus on a specific aspect of a patient and their disease, and not on the patient and their family system as a whole.

O'Connor et al. (18) stated the importance of open communication between the different professionals in a team as key, in order to ensure that a patient is receiving the best care possible. Irwin et al. (38) also highlighted the importance of improving the communication and the co-ordination of a palliative patient's care from their medical team.

Patients and their families need to also be included in the communication and in team collaboration. The patient remains the expert on what they consider to be a good quality of life, yet they are often not part of the conversation when looking at the treatment options and the goals of care. By including patients in these sometimes-difficult conversations, Irwin et al. found that patients were less likely to receive aggressive, and often futile treatment, when they were actually in the end-of-life phase of their disease (38).

Participants in this study acknowledged that they often introduced difficult conversations only when treatment had failed, resulting in the family's expectations needing to be managed, as they may be holding on to the idea of their family member being cured, and that the doctors will continue to do everything possible to cure them. Yet, as was shown in Best et al.'s study (36), if these honest conversations are held early on, then patients and their families can reset their goals, and often prevent futile treatment. This could lead to families having more realistic expectations and fewer requests for ongoing futile treatment in the terminal phase, allowing the focus to shift from cure to care, and this can improve a patient's overall quality of life.

The findings of this study also highlighted the issue of doctor's time constraints as a barrier to good communication with the patient's family. Doctors acknowledged the importance of keeping patient's families well informed and managing expectations but felt that there was just no time to engage in these important conversations. This has been noted in a previous study by Selman et al. (2009) who also looked at the information needs of palliative care patients and their families in SA and in Uganda, and they also noted healthcare professional time constraints as a barrier to meeting the information needs of patients and their families (76).

5.6 Spiritual Care

Providing spiritual care is part and parcel of providing palliative care, but the initial reaction of most of the participants in this study was that they had no role to play in providing spiritual care to their patient, as they were not qualified to do so. This is in keeping with the literature, in which studies have shown that doctors do not feel that they are adequately equipped to address a patient's spiritual needs, as they do not receive training in spiritual care (77). This leads to spiritual concerns not being discussed, resulting in patients being non-responsive to pain medication because an important component of their pain has not been addressed, hindering proper pain management (73).

The findings of this study revealed that, despite the fact that most of the participants in this study did not feel that they should provide spiritual care, they did acknowledge that their patients often initiated spiritual discussions. Most of the participants responded that they would then refer these patients to a religious leader, for example: a priest, an imam, etc. Yet, more and more evidence suggests that a doctor's role in spiritual care is not merely to gather information and refer a patient on to an expert, but rather to engage with the patient in establishing their spiritual history, as this may open up conversations about concerns around end-of-life decisions (77). Peteet et al. (2011), went on to state that the more closely a religious view impacts, or is connected to, the treatment of a patient's physical disorder, the more important it is for a doctor to engage in, and understand the issue (78). Spiritual care does need to be addressed by the multidisciplinary team, and the doctor does have a role to play.

Some of the participants in this study also felt that the large variety of religious beliefs in SA further complicated spiritual care. This resulted in an avoidance of spiritual conversations due to the fear of offending a patient or even a colleague, due to clashing beliefs, and therefore they felt that spiritual interactions should be avoided altogether. The problem with avoiding spiritual care altogether, is that spirituality plays a big role in improving a patient's quality of life. Various studies by Mehta and Chan (73), Nawawi et al. (77) and Best et al. (79) have shown that patients who experience higher levels of spiritual well-being, enjoy life more and have a better overall quality of life, in spite of the high burden of physical symptoms they experience. It is therefore imperative to provide a patient with spiritual care if there is a desire to improve their overall quality of life.

Nawawi et al. went on to say that patients facing a life-threatening illness want their medical team to play an active role in addressing their spiritual needs, as it is viewed as part of their medical care

(77). While most of the participants in this current study acknowledged that patients facing a life-threatening illness required spiritual care, all but two of the participants felt they had no role to play in providing it. The participants who did feel that they had a role to play, added that the role was small and due to time constraints, it remained challenging to properly engage in these important conversations. Yet the current COVID pandemic has highlighted how spiritual care is a necessity and how it cannot always be addressed by a spiritual care specialist. It therefore calls for all doctors to improve their spiritual care delivery practices (50).

A lack of training in the skills needed to provide spiritual care, and also the extreme time constraints faced by doctors in SA, spiritual care continues to be a barrier in the provision of good palliative care and also "total" pain control. While it remains important for doctors to be open to spiritual discussions and care for their patients, they can also get the team involved to help address the "total" pain of a patient.

5.7 Limitations of this Study

The researcher currently works in the hospital setting where the study was conducted. The researcher therefore came into the study with pre-existing views and experiences of palliative care and how it is currently being provided for in the hospital. Continuous self-awareness and reflexivity of these values, beliefs and possible bias was done throughout the study to ensure that objectivity was maintained, as discussed in Chapter 3.

The researcher had worked with a few of the participants in this study. These previous relationships could have influenced the participants willingness to participate in the study. The researcher ensured that all the participants were invited to be part of the study in the same way, as to not manipulate the participants who are known to her.

Due to this study's use of a qualitative approach, the main goal was to collect in-depth information, resulting in a deeper understanding of doctors perceptions and provision of palliative care, however this has lead the study to lack generalizability that one usually obtains in quantitative studies.

5.8 Strengths of the Study

The study included a variety of specialists, giving a richer understanding of the perceptions and the provision of palliative care amongst different specialties, and not just a select few. This was important, as the call is for palliative care to be integrated into the health care system as a whole, so that it can be part of the comprehensive care that all patients receive. All doctors therefore need to be equipped and have a good understanding of palliative care so that it can be provided (1).

The researcher is an experienced interviewer and has very good communication skills, due to her training as a social worker. The researcher's knowledge of palliative care was also an asset. This allowed for the participants to be probed further during the interview process, allowing for rich data to be collected, which is important when conducting qualitative research. Credibility was assured by making use of triangulation, in which conclusion were drawn from the data collected during the interviews, together with the observations made and field notes kept. Continuous self-reflection was done throughout the interview process to ensure that open-ended questions were asked, so that the voice of the participants were heard, without being influenced or guided by the researcher.

A final strength of the study was that the participants varied in age, which allowed the researcher to be aware of the changes that are starting to take place in terms of the palliative care training that doctors are receiving at university during their undergraduate training.

CHAPTER 6: CONCLUSION AND RECOMMENDATIONS`

6.1 Introduction

With the adoption of the WHA Resolution 67.19 in 2014 by SA, there was a call for palliative care services to be integrated into all health care systems. This study aimed to look at what the doctor's current perceptions of palliative care were, as well as the role that doctors are playing in providing palliative care, in the private hospital setting, and to see if palliative care is being integrated in the private health care sector. This chapter will discuss the conclusions drawn by the researcher, from the findings made in relation to the studies objectives and thereafter, recommendations for the future will be made.

6.2 Findings Linked to the Study Objectives

Objective one of this study was to explore the doctors' experiences of pain control and symptom management in palliative care. WHO's analgesic pain ladder which is the main tool used in palliative care to guide doctors on effective pain and symptom management was well known but was not really used. Morphine was also not used by all. Overall, the study's participants did strive to ensure that their patients pain needs were addressed, especially in the end-of-life phase of a patient, in which most participants were more open to the use of morphine. There was also an awareness of the possible side-effects from various pain medications, and most of the participants tried to be proactive in addressing these. Most of the participants also discussed the possible side-effects of morphine with the patient's family, but not with the patient.

Objective two of this study was to explore the doctors' perceptions of palliative care, goals of care and teamwork in palliative care. Palliative care was mostly perceived to be end-of-life care, when there were no longer any active treatment options for the patient, which is in keeping with the literature. The study participants in general did not know the role that palliative care can play early on in the diagnosis of a life-threatening illness and still associated palliative care to hospice. Palliative care was also seen as an approach for cancer patients only. There was however a clear understanding of some of the goals of palliative care, namely improving the quality of life of a patient, ensuring that the patient's dignity is maintained, and keeping a patient comfortable and pain free.

Although a teamwork approach to palliative care was adopted in the Oncology setting of the study site, this was not seen within the other participants specialties. Members of the multidisciplinary team had patients referred to them for further care, which is a good starting point, but these healthcare professionals were working independently of each other.

Objective three was to explore the doctors' provision of palliative care at the hospital. Although many did not immediately pinpoint a role that they were playing in providing palliative care and many even stated that their goal was to cure, with further probing it become clear that some of the doctors were playing a role in providing some palliative care. However, many of the participants still did not think that they had a role to play, because of the view that palliative care was care for a dying patient.

6.3 Recommendations

From the literature reviewed and the findings made in the study, the researcher recommends the following as a means of more actively integrating palliative care into the private hospitals.

1) *Further research to be conducted in private hospitals.* This study was only conducted in one private hospital. It would be beneficial to conduct this research in more private hospitals in order to assess whether doctors have similar perceptions and experiences of palliative care, and to estab-

lish whether palliative care is part of the continuum of care being offered to patients in the private sector. This will highlight the barriers that need to be overcome in order to make palliative care more accessible to patients and their families.

2) *Engage with management and doctors to begin the process of offering more formalised palliative care services at the hospital.* As has been mentioned throughout this study, palliative care needs to be part of the continuum of the care that patients receive. In order for this to become more of a reality in the hospital where the research was conducted, steps can be taken by management to engage with the available policies, such as the NPFSPC. Doctors and members of the multidisciplinary team who are both equipped with palliative care skills and who are also passionate about it (e.g. PALPRAC), can also be contacted, to offer suggestions and possibly begin the process of putting a palliative care team in place. A team approach *could have multiple benefits, such as more open communication between the members of the multidisciplinary team, as well as the patient and their family. It could also lead to a patient being viewed as a whole, and not being compartmentalised by the different members of the multidisciplinary team.* It will therefore also be vitally important to discuss the findings of this research with both doctors and management, giving them the opportunity to provide their own input and also encouraging more ownership of the development of palliative care in the hospital.

3) *Networking with palliative care service providers.* It will be beneficial to connect with the current available palliative care services in the area, to open up the communication channels with these services, and to also ensure that patients are actively linked to these services. It may also be beneficial to connect with a private hospital that does have a palliative care program in place and learn how they implemented these services in their setting.

4) *Organising palliative care training and interactive workshops.* Both the literature reviewed and the findings in the study have pointed to the gaps that still exist in the doctor’s education when it comes to palliative care. Organising Continuous Professional Development (CPD) training around palliative care topics and interactive workshops, may help the doctors and other health care professionals to engage in important debates in palliative care. Important topics to cover would be pain control, morphine myths, the benefits of early palliative care, working as a team, communication skills and spiritual care, to name a few, but there are many more that could be beneficial.

5) *Palliative care awareness campaign.* An awareness campaign held in conjunction with *World Hospice and Palliative Care Day,* which is held annually in October, could provide an opportunity to improve the knowledge of palliative care amongst healthcare professionals as well as the patients and their families. It will provide more opportunities for networking to take place, and hopefully increase the available palliative care resources, as well as to make the patients and their families aware of how to access these resources.

6.4 Concluding Thoughts

Palliative care was seen as an important intervention for a dying patient by the participants in this study, but by only introducing these services at the end-of-life phase, it prevents one of the main goals of palliative care being achieved, which is to improve the patient's and the family's quality of life. There was however a recognition that palliative care was being introduced too late. Some doctors were offering palliative care services, even if they did not always label it as such. The next step will be to disseminate these findings, to advocate for awareness and standardised palliative care training at all medical school, so that palliative care becomes more accessible to all patients in SA as part of the continuum of care across their lifespan.

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APPENDICES

APPENDIX A: INTERVIEW GUIDE

Perception

1) When you hear the word palliative care, what comes to mind?
    a) Why do you think that comes to your mind?
    b) What would you say is the main goal of palliative care?
2) What is your specialty/position/role in this hospital?
    a) Do you think palliative care is relevant to your specialty?
    b) Please elaborate.
3) Do you get patients referred to you for palliative care?
4) Do you refer patients for palliative care?
5) According to your understanding, what are the goals of care for patients referred for palliative care?

Experiences and views on pain management

6) Have you heard of WHO's Analgesic ladder for pain relief?
    a) If yes, do you use it?
    b) Please explain how you use it.
    c) Has it been helpful?
7) How comfortable are you in prescribing strong opioids?
8) Which strong opioids do you usually prescribe?
9) How do you feel about prescribing morphine?
    a) How often do you prescribe morphine?
    b) Do you discuss the side effects of morphine with your patients and/or their families?

c) How do you explain the side effects?

Multidisciplinary Team

10) Do you involve others in the management of your palliative care patients?
    a) If yes, who do you involve and why?
11) Family members of a patient with advanced illness require support. How do you provide this support?
12) As a doctor how do you identify patients experiencing spiritual distress/discomfort?
13) Does a doctor have a role to play in the spiritual care of a patient?
    a) Please elaborate.

APPENDIX B: HUMAN RESEARCH ETHICS COMMITTEE APPROVAL LETTER

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 6626
Email: shuretta.thomas@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

08 August 2019

HREC REF NO: 448/2019

Ms Linda Ganca
Public Health and Family Medicine
Falmouth Building

Dear Ms Ganca

PROJECT TITLE: *AN EXPLORATION OF DOCTORS' PERCEPTIONS AND PROVISION OF PALLIATIVE CARE AT A PRIVATE HOSPITAL IN GAUTENG, SOUTH AFRICA (MPHIL CANDIDATE - MS E BOOTH)*

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

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

Approval is granted for one year until the 30 August 2020.

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.

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

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

The HREC acknowledge that the student, Elizabeth Cecile Booth will also be involved in this study.

Yours sincerely Signature Removed

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938
This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical

APPENDIX C: INFORMATION SHEET

An exploration of Doctors' perceptions and the provision of Palliative Care at a Private Hospital in Gauteng, South Africa

Thank you for taking time to hear about my study.

This information sheet tells you about the study that I am currently conducting, that you may wish to partake in. You may have more questions that you would like to ask before deciding whether you wish to take part in this study. You can ask any further question you have to myself (the researcher); my contact number is listed below.

Thank you for considering being part of this study. Please take your time in making this decision.

What is the purpose of this study?

I would like to explore the Doctors' perceptions and provision of Palliative Care in the Glynnwood Hospital.

Do I have to take part?

No, you do not have to take part. This research is on a voluntary basis. If you do agree to take part in the study, you may withdraw from the interview at any point, and you do not need to provide any reason for your withdrawal. If you do agree to take part in this study, you will be asked to sign a consent form, in order to show that you have agreed to do so.

Description of the study's procedure

I will conduct a one-on-one interview, and I will be asking questions about palliative care in order to discover your current perceptions about palliative care. I will also be exploring your current palliative care interventions with your patients. To ensure confidentiality, interviews will be conducted on a one-on-one basis, in a private office and will take approximately 45 minutes each. A tape recorder will be used to record the interview, and this will be a once off interview. The recorded interview will then be transcribed, and your name will not appear on the transcribed interview or in the research findings. Instead a number will be allocated to you, which will be used for all information pertaining to you. All information will be kept on a password-protected laptop. and any written notes will be locked away in a cupboard and shredded once the research is completed. Tape-recorded interviews will be destroyed once they have been transcribed.

This information sheet is for you to keep.

Benefits of the study

There are no direct benefits if partaking in this study. The hope is that this study will increase the provision of palliative care by establishing what is currently working, as well as highlight any gaps there may be.

What are the risks?

There are no risks in partaking in this study.

Will my taking part in this study be kept confidential?

All information collected from you during the study will be kept confidential. Your name will not appear in the study, and instead a number will be assigned to the information you provide. Your specialty may be recorded.

How will I know about the results of the study?

A report on the findings of the study will be provided to each doctor who participated in the study.

Who is organizing the research?

If you need to talk to anybody about the research or if you have question about the study, you can contact the following people:

Cecile Booth: 082-928-0711

If you have any concerns regarding the study:

Linda Ganca, Research Supervisor,
University of Cape Town.
Telephone: 021-406-6590

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

UCT Research Ethics Committee:
Mrs Lamees Emjedi

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

APPENDIX D: CONSENT FORM

An exploration of Doctors' perceptions and the provision of Palliative Care at a Private Hospital in Gauteng, South Africa

1. I confirm that I have read and understand the information sheet and I have had an opportunity to ask questions.
2. I understand that my participation in this study is voluntary and I am able to withdraw from the study at any time, and do not need to give a reason for my withdrawal.
3. I agree to take part in the study above.

Name ________________________________

Signature _____________________________ Date ________________

Researcher: Signature __________________ Date: _______________

Witness: Name

Signature ______________________________ Date: _______________