An Exploration of Factors that Influence Referrals to Palliative Care in Oncology

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Declaration

I, **Nosisa Matsiliza** 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

ASCO	American Society for Clinical Oncology
EAPC	European Association for Palliative Care
ECOG	The Eastern Cooperative Oncology Group
ED	Emergency Department
EOL	End of life
EPCR	Early palliative care referral
ESMO	European Society for Medical Oncology
FACT-L	The Functional Assessment of Cancer Therapy-Lung
HADS	Hospital Anxiety and Depression Scale
HIV	Human Immunodeficiency Virus
HPCA	Hospice Palliative Care Association of South Africa
HREC	Health Sciences' Human Research Ethics Committee
HRW	Human Rights Watch
IAHPC	International Association for Hospice and Palliative Care
IARC	International Agency for Research on Cancer
IV	Intravenous
LPCR	Late palliative care referral
MVQOLI	Missoula Vitas Quality of Life Index
NSCLC	Non-small cell lung cancer
OP	Oncologist Participant
PC	Palliative Care
PALPRAC	The Association of Palliative Care Practitioners of South Africa
PatchSA	Palliative Care for Children South Africa
PP	Patient Participant
SACO	South African Congress of Oncology
SAOC	South African Oncology Consortium
SDM	Shared Decision-Making
SPICT	Supportive and Palliative Care Indicators Tool
SPICT-SA	Supportive and Palliative Care Indicators Tool-South Africa

QOL	Quality of life
TPN	Total Parenteral Nutrition
UCT	University of Cape Town
WHA	World Health Assembly
WHO	World Health Organization
WHOWOL	World Health Organization Quality of Life Assessment Group
WHPCA	Worldwide Hospice Palliative Care Alliance

Contents

Abstract:

Background: Globally, cancer is a leading cause of death. The impact of cancer is higher in low-middle income countries, compared to middle-high income countries. In Africa, the WHO projects a 403% increase in cancer between 2016 and 2060. There is convincing evidence that there are benefits to patients in providing palliative care together with oncology treatment. These benefits include understanding of prognosis, improvement in quality of life, and an increase in satisfaction with care for the patients. However, in South Africa, there is a paucity of early referrals to palliative care.

Aim: The aim of the study was to determine factors that influence referral of patients with cancer, to palliative care services.

Methods: This was a qualitative cross-sectional study allowing for in-depth exploration of participants' views. There were two groups of participants 1) adult patients diagnosed with cancer, and already informed of their diagnosis; 2) medical and radiation oncologists. Purposive sampling was undertaken with planned sample size of 10-14 patient participants and 8-10 oncologist participants The participants were fully informed regarding the research and asked to sign consent to take part in the research. In-depth interviews were conducted following interview guides – for patients and for oncologists. Thematic analysis was conducted manually by the researcher with the support of the supervisor, and themes derived from transcripts of the participants' interviews.

Results: Participants were twelve patients with cancer and eight practising oncologists. Five major themes were identified: 1) Experiences of care; 2) Relationship between oncology and palliative care; 3) Patient views on referral to palliative care services; 4) triggers for referral to palliative care services; 5) Practical considerations in referral to palliative care services. Key findings were the need for good effective communication, providing enough information to enable patients to make informed choices, a need met by palliative care services but not by oncologists whose communication manner was hurtful, without compassion and empathy and left patients unclear or overwhelmed. There is a difference in the understanding of palliative care by oncologists, while patients saw a need for early referral to palliative care services.

Conclusion: The quality of life in patients with advanced cancer is negatively affected by oncologists' lack of effective communication. These patients, referred late to palliative care services, remain with unmet information needs. However, they are highly appreciative of palliative care services even when they are referred to these services near the end of their lives. Patients with advanced cancer may benefit more with early referral to palliative care services, while oncologists' communication skills and understanding of what palliative care is, may benefit from palliative care training.

Chapter One: Introduction

Epidemiology of cancer

Globally, cancer is a leading cause of death (Torre et al., 2015). In 2018, about 17 million cancers were diagnosed worldwide, with 9.5 million deaths (Ferlay et al., 2019). In the United States of America, more than 1.7 million new cancers were expected to be diagnosed in 2019. These estimates excluded carcinoma-in-situ of any site, except bladder cancer. They also excluded both basal and squamous skin cancers (American Cancer Society, 2019). Indeed, the cancer cases worldwide keep on increasing. An updated report of the IARC shows that an estimated 19.3 million new cancers and almost 10 million deaths occurred in 2020, and the global burden of new cancer cases is expected to rise by 47% on the 2020 figures, by 2040 (Sung et al., 2021). This increase is associated with growth and aging of the population. In Africa, this rise is estimated to be about 89% on the 2020 figures (IARC, 2023)

Thus, worldwide, there is a high burden of disease from cancer. South Africa falls within the less developed regions, with a high burden of disease but less resources to achieve high cure rates. The WHO Global Cancer Statistics 2020 shows the National Ranking of Cancer as a cause of death in ages 0-69 (2019). In this report South Africa ranks cancer as the 3rd-4th cause of death in this age group, compared to first world countries where cancer is ranked as the 1st cause of death (Sung et al., 2021). However, this ranking belies the real impact of cancer on the South African healthcare system, as well as the physical, psychosocial and spiritual burden on both patients and their families. The high morbidity and mortality associated with cancer suggests that there is need for palliative care intervention in patients diagnosed with cancer.

Palliative Care Policy Development

In 2014, the sixty seventh World Health Assembly “realised the urgent need to include palliation across the continuum of care, recognizing that inadequate integration of palliative care into health and social systems is a major contributing factor to the lack of equitable access to such care” (World Health Assembly, 2014). Resolution WHA67.19 included the need “to create or strengthen health systems that include palliative care as an integral component of the treatment of people within the continuum of care”(World Health Assembly, 2014). The

South African government has signed up to the 2014 WHA resolution. Furthermore, with the National Health Council approving a Policy Framework and Strategy for palliative care in South Africa in 2017 (National Department of Health, 2017), it has become mandatory that all health professionals be trained in palliative care. A survey by Krause et. al, at the University of Cape Town Palliative Care department and Groote Schuur hospital demonstrated the need for and acceptability of integrative palliative care services training amongst oncology registrars at these two institutions (Krause et al., 2018). This gives hope that the Policy Framework and Strategy may be implementable.

In their "Ethical Guidelines on Palliative Care", published in 2019, the Health Professions Council of South Africa (HPCSA) states that "Palliative care is provided by all health practitioners and other health care professionals working with people with life-threatening conditions". While the HPCSA speaks about ***all*** health practitioners and other health care professionals *working with people with life-threatening conditions*, there is no specific reference to oncologists They further state that "Health practitioners providing palliative care should possess the requisite knowledge, skills and attitudes to meet the physical, psychological, practical, social and spiritual needs of their patients". However, the HPCSA , currently, has no way of enforcing these guidelines. It may be helpful and in line with the Department of Health National Policy Framework and Strategy on Palliative Care 2017-2022, if the HPCSA would make it a requirement to have continuing professional development (CPD) in palliative care for all health care professionals.

The South African Nursing Council does not include palliative care as part of basic nursing education and training. Palliative nursing care is included only in oncology nursing training.

What is Palliative Care?

The World Health Organisation (WHO) defined palliative care "….as an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment of pain and other problems, physical, psychosocial

and spiritual" (World Health Organisation, 2002). Palliative care "is applicable early in the course of the illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications" (World Health Organisation, 2002). Importantly, palliative care acknowledges the importance of the interconnectedness of the patient and family in life-threatening illness. It acknowledges the disruption of the family system at a much deeper level than just the physical level. The disruption occurs irrespective of prognosis, even for those cancers that are curable, resulting in deep psychosocial and spiritual need for support (Grassi & Rosti, 1996). Grassi and Rosti have shown the need for continued psychological care in patients that have passed the 6-year survival mark, by showing that even in these patients the prevalence of psychiatric disorders was still high at thirty seven percent (Grassi & Rosti, 1996).

Principles of Palliative Care

There is convincing evidence that implementing the principle of early palliative care is feasible and that there are benefits, including understanding of prognosis, improvement in quality of life, and an increase in satisfaction with care for the patients (Greer et al., 2013; Jacobsen et al., 2011; Kavalieratos et al., 2016; Temel, Jennifer S. et al., 2011). However, in South Africa, even with the existing palliative care systems, such as trained palliative care practitioners and facilities such as hospice, there is still paucity of early referrals of oncology patients. Several reasons could account for this practice, including the low numbers of trained palliative care clinicians (Lubuzo, Ginindza & Hlongwana, 2019). The reasons could also be patient/family-related(Ward, Agar & Koczwara, 2009), while they could also be related to oncologists' preferred practices. The oncologists' practices may be influenced, amongst others, by prognostic uncertainty, (Temel, J. S., Shaw & Greer, 2016) as well as a sense that a palliative care referral seems to be an abandonment of the patient (Back et al., 2009).

However, other key principles of palliative care include the use of "a team approach to address the needs of patients and their families, including bereavement counselling…", as well as integration of "the psychological and spiritual aspects of patient care" (World Health Organisation, 2002). These principles suggest that, if applied optimally to patients diagnosed

with cancer, this would include the oncologist as one of the team members, and the sense of abandoning the patient could be reduced significantly. The patient and family, if referred early in the course of their disease would have had the opportunity to build a trusting relationship with the palliative care team members. As such, the stage at which the curative treatment becomes less, while palliative care increases would not be an abrupt change causing disruptions to established relationships. There is a need to build relationships across multiple health systems and specialities (Von Roenn, Voltz & Serrie, 2013). Failure to uphold, to any degree, these key principles of palliative care, may result in poor referral practices. A number of studies have come to certain conclusions, regarding barriers to palliative care referrals. (Miyashita et al., 2008; Ward, Agar & Koczwara, 2009).

International Perspective

In Australia, Johnson et al, in their study of palliative care providers' perceptions, found that while providers considered palliative care as an holistic approach, whose success could be measured by good symptom management, the same providers could not nominate a specific time or milestones for such referrals to occur (Johnson, C. et al., 2011). In the Johnson et al.'s group of participants, referrals for symptom management seemed to be more common than referrals for other end-of-life issues. There might be more success in early referrals, were palliative care practitioners to concentrate on more on their role in symptom management, ahead of the holistic approach of palliative care. A further point raised by Johnson et al.'s study was that among health care professionals and patients, a suggestion to refer to palliative care services is perceived as a suggestion that the patient is about to die(Johnson, C. et al., 2011). This belief may be contributing to late referrals to palliative care services.

On the other hand, a survey conducted by Ward et al. in South Australia, investigating attitudes of medical oncologists toward collaboration with specialist palliative care services, showed positive attitudes. Most respondents preferred concurrent participation in the care of the patient (Ward, Agar & Koczwara, 2009). Among the reported barriers were reluctance on the part of the patient and families for a palliative care referral. The study involved only medical oncologists and all results reflected only the oncologists' perceptions. However, it is worth noting that the majority of oncologists had a collaborative relationship with specialist palliative care services, accessing these services, at least weekly

Miyashita et al., in their Japanese study, found that the leading barrier to referral was the negative image of palliative care units as perceived by patients and families (Miyashita et al., 2008). Other significant barriers, in this study, were the delay in the termination of anti-cancer treatment by oncologists, this possibly being due to the difficulty in prognostication, as well as the collaborative unwillingness to end anti-cancer treatment by patient and family (Miyashita et al., 2008). Both the reluctance by the oncologist to terminate anti-cancer treatment, and the patient and family reluctance to stop anti-cancer treatment, even when there is no improvement in general indicators of poor or deteriorating health, reinforce each other, probably resulting in delay in referral to palliative care services. This suggests that palliative care services are only there when there is no longer hope for cure, which in the experience of the researcher can be anything from a few days to a few weeks before the patient dies. This “last resort” referral practice, robs both patient and family of optimum care and quality of life.

ESMO guidelines have been drawn to recommend earlier integration of palliative care services(Peters et al., 2012; Smith, Thomas J. et al., 2012). However, in a survey of specialist physicians, Smith et al. showed that nearly fifty percent of physicians practising in New York City, reported referring less than 25% of their patients to palliative care services (Smith, C. B. et al., 2012) , even when outpatient palliative services have been rapidly expanding across the United States (Hui, David. et al., 2010; Rabow et al., 2010). Widely varying frequency and timing in referral to palliative care services has been reported in Canada and Europe (Cherny, Nathan I. & Catane, 2003; Smith, C. B. et al., 2012; Wentlandt, Kirsten. et al., 2012). Yet a different set of barriers to palliative care referral by oncologists was identified by Schenker et al. (Schenker et al., 2014). In this qualitative study conducted by Schenker et al., oncologists viewed palliative care as an “alternative philosophy of care incompatible with cancer therapy”(Schenker et al., 2014). Furthermore, oncologists believed that palliative care was an integral part of the oncologist’s role, while also citing lack of knowledge of locally available palliative care services. It is unclear whether the palliative care that is seen to be an integral part of an oncologist’s role applies the same holistic palliative care principles as defined by the WHO, and practised by qualified palliative care clinicians.

From these studies, it seems that there is a fairly wide variety of barriers to palliative care in general, amongst the international community. It may be that specific local circumstances determine which particular barrier predominates in slowing palliative care referrals.

Palliative Care in South Africa

There is no specialist palliative care in South Africa. In this context there is primary palliative care offered by general practitioners who have received specialised training in palliative care, as well as by hospices. Most of the generalists work in the private sector/non-governmental sector. Hospices are also non-governmental. Referrals to these primary care services have been erratic, by individual oncologists while a significant number has been self-referral by patients or family members. Oncologists receive no palliative care training during their oncology training. This may result in failure to recognise and understand the complexity of oncology patient needs as well as the breadth of care provided by palliative care practitioners. This lack of palliative care training by oncologists may be the strongest barrier for referrals to palliative care services.

In the government/public services, there is very little palliative care offered, with small but prominent palliative care centres in some secondary and 2 tertiary hospitals.

It has been established that there is significant paucity of referral of oncology patients to palliative care services, even in well-resourced parts of the world, where clear guidelines have been established for such referrals. In South Africa, the National Policy Framework and Strategy on Palliative Care approved in 2017, has been taken further, in the appointment of a Deputy Director responsible for palliative care coordination. The appointment of the Deputy Director has resulted in the formation of groups of palliative care expert practitioners that have been tasked with drawing up palliative care guidelines, to be incorporated into the National Health Policy. This has been an encouraging development, creating hope for growth of palliative care practice in South Africa. However, the hospice movement that has been at the forefront of advocacy and provision of palliative care in South Africa has, so far, been unable to attract early palliative care referrals at the scale required by the extent of the burden

of need. There has been some increase in hospital-based palliative care, for example at Groote Schuur hospital and at Baragwanath hospital. The Association of Palliative Care Practitioners of South Africa (Palprac), was formed in 2018, as an association for accredited practising palliative care doctors in South Africa (Palprac, 2018). It is hoped that the formation of a formal body of accredited palliative care practitioners will boost the efforts of integrating palliative care to current medical practice in South Africa, for the benefit of patient and family. Indeed, Palprac was a recognisable force behind the resounding success of the recent Palliative Care Conference, held in Cape Town, from 26-29 April 2023. The co-organisers of the conference were Palprac, Palliative Care for Children South Africa (PatchSA) and the Hospice Palliative Care Association (HPCA). The collaboration between these three palliative care organisations, resulting in conference attendance of more than 400 delegates, may be a signal of a new visibility of palliative care in South Africa. However, the conference also revealed that in South Africa, only 18% of people needing palliative care actually have access to it, and that the number of hospices has more than halved, over the past decade because of financial problems (South African Palliative Care Conference, 2023). This demonstrates a clear need to finalise and implement national palliative care guidelines with a sense of urgency.

Why does family matter?

Palliative care is…"an approach that improves the quality of life of the patient and their families……."(World Health Organisation, 2002). The family is the fundamental unit of existence in society (Filipek, 2020; Florea, 2022). It can be considered as a system, with multiple components and a shifting dynamic, much like a business entity. Furthermore, there is the added dimension of emotional connectedness. "Fundamentally, there is a need to understand the entire context in which people experience and make sense of their illness, and particularly their interconnectedness with others"(Illingworth et al., 2010). A disruption at any level of functioning within the family is, thus, expected to be felt throughout the family system. The psychosocial effects of cancer have ripple effect throughout the family"(Lewis, 1990), disrupting family identity and daily routines (Blanchard, 1997; Lewis, 1990). Palliative care, with its holistic approach of looking after physical, psychosocial and spiritual effects of

disease and illness, is uniquely suited to support such families, while oncologists, without palliative care training, are unlikely to be able to offer these families such holistic support.

Families provide a key context for adjustment by the patient with cancer (Blanchard, 1997). This context can have positive or negative effects on how a patient responds to the diagnosis and treatment of cancer. Enmeshment or disengagement of families, both considered pathological (Olson, 2000), are likely to impact patient adjustment. Families are also directly affected by the illness. There is evidence that family members of cancer patients also suffer from stress. Amongst the causes of distress are the fear of cancer and its spread, fear of dying of the affected member of the family, the unpredictability and thus uncertainty of the disease course(Blanchard, 1997), amongst others. The loss of control associated with unpredictability and uncertainty is likely to have a profound effect on everyday functioning of a family. The socioeconomic status of the family has been shown to influence the extent of the distress, with lower status exhibiting the greatest strain (Blanchard, 1997; Sales, Schulz & Biegel, 1992). An added dimension is that many patients with advanced cancer would prefer to be cared for, and to die at home (Dunlop, Davies & Hockley, 1989; Fereidouni et al., 2021; Higginson, I. J. & G. J. A. Sen-Gupta, 2000). Such a trend will, no doubt, change the family roles into caregiver roles for the patient diagnosed with cancer. All of these family dynamics will have an impact on the adjustment by the patient with cancer, as well as an impact on the adjustment of the family of the patient with cancer, requiring comprehensive support from the palliative care team.

The family at risk

With advances in medical science, treatment modalities and technology, there are many more cancer survivors. However, even with this advancement there are still many who die from cancer. Furthermore, cancer is a disease that occurs in any age group. Thus, every family where cancer is diagnosed is at risk. “In the event of cancer the whole family system is at risk, and so are individual family members”(Wozniak & Izycki, 2014)

A family system is a net of mutual relations ((Wozniak & Izycki, 2014), unique to each family. Cancer can have a considerable impact on marital relationships, with problems including

communication, quality of sex life, role reversal amongst others. At the different stages of the "cancer journey" one may find different responses by both patient and family.

For adults the diagnosis of cancer brings fear: fear about the threat to life itself, about treatment options with all the associated possible side effects of the individual treatment modalities, including but not limited to alteration of self-image; fear about poor response to treatment; fear about loss of intimacy with partner; fear of loss of income and fear about loss of established roles in the family structure. For parents of children diagnosed with cancer, they describe it as the most overwhelming experience of their lives(Wozniak & Izycki, 2014)

For children, having a parent diagnosed with cancer can also lead to a lot of distress. Even though they may find it difficult to define their emotions, these may include anger, grief, and feelings of rejection. They may also see it as some sort of punishment, and that they are responsible for their parent's sickness (Wozniak & Izycki, 2014).

A further risk to patients and their families is that of financial distress as a result of loss of income and an increase in out-of- pocket expenses related to high cost of treatment. The financial burden carried by caregivers of cancer patients is disproportionately high compared to that carried by other caregivers because of the intensity of care required for cancer patients and the cost and complexity of treatment for these patients (Bradley, 2019). Cancer is one of the most expensive medical conditions to treat (Soni, 2001). Palliative care can substantially reduce healthcare costs among advanced cancer patients (Yadav et al., 2020), and palliative care applied earlier, results in greater cost savings (Sheridan et al., 2021). The widespread use of non-beneficial treatments at the end of life, in acute hospitals (Cardona-Morrell et al., 2016) may be significantly reduced by early referral to palliative care services.

It is, thus, clear that a diagnosis of cancer puts the whole family at risk. Caring for such a family requires a comprehensive approach that not only looks at the physiological requirements of care but also the psychosocial and spiritual needs of both the patient and the family.

The specialised discipline of Palliative Care is well suited to meet the needs of these families.

Chapter Two: Literature Review

The searches were conducted using *Pubmed* and *Google Scholar.* The following literature search strategy was applied. The topic of study was used as the starting point for the literature search. The key words *palliative, care, referral, oncology, factors, influence* were used in combination of at least two words, which were further refined to phrases without inverted comas or in inverted comas, to conduct a basic search. The joining word 'AND' was used between different ideas, thus focusing the search results. On the other hand, the joining word OR' was used between different ways of expressing the same idea. Where certain authors have already published seminal papers, the search was conducted using the name of the author, in order to identify additional published literature under the same author. Specific relevant articles obtained from the reference lists of papers already reviewed were also searched for, directly. As the discipline of palliative care is a relatively young one, and the researcher is new to this field of research, the search was not limited by date. The results were reviewed for relevance to the study. From the first articles viewed as being relevant, further selected searches were made from the bibliographies. Below is the review of the literature.

Cecily Saunders, considered to be the founder of the modern hospice movement and palliative care, made this statement about the patient "You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die" (Saunders, 2000). From this statement, still applicable to today's palliative care, there is evidence of the importance placed on the patient, the team that looks after the patient, the quality of life for the patient and family and living life until death occurs. But perhaps, by starting with "we will do all we can not only to help you die peacefully" Cecily Saunders was putting emphasis on the focus of the day for patients with serious illness, when palliative care was considered to be end-of-life care. Indeed, the hospice and palliative care model, established outside the main health care systems in the 1960s, primarily focussed on end-of-life care ((Kaasa et al., 2018). However, the definition of palliative care by the World Health Organisation (WHO) below, differs from this earlier end-of-life approach and states

that palliative care should be applied early on in the disease trajectory (World Health Organisation, 2002).

Early Integration of Palliative Care

The WHO defines Palliative Care as "An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (World Health Organisation, 2002). This definition of palliative care illustrates the holistic nature of the discipline of palliative care. Principles that stand out from this definition include the principle that palliative care should be implemented early on in the disease trajectory, suffering from pain and other symptoms, physical, emotional or spiritual should be comprehensively assessed and managed effectively and the quality of life of both patient and family should be enhanced. This early integration of palliative care, as defined by the WHO has been supported by international professional organisations. Amongst others, the European Society for Medical Oncology (ESMO), the American Society for Clinical Oncology (ASCO) and the European Association for Palliative Care (EAPC) have identified palliative care as an integral part of oncology care (Cherny, N. et al., 2010; Smith, Thomas J. et al., 2012). The European Association for Palliative Care (EAPC), the International Association for Hospice and Palliative Care (IAHPC), the Worldwide Hospice Palliative Care Alliance (WHPCA), and Human Rights Watch (HRW) further formulated the Prague Charter to advocate for access to palliative care as a human right (Radbruch et al., 2013) . In their petition, this coalition urged national governments of all countries to develop health and social policies that ensure relief of suffering through patient-centred palliative care. Further support for this concept of full integration of palliative care and oncology, has been provided by several randomised clinical trials.

Indeed, in different studies, Temel, Jacobsen, Kavalieratos and Greer, amongst others, have shown that early palliative care is feasible and impacts positively on quality of life, understanding of prognosis, improved survival, with less anxiety and depression, and an increase in satisfaction with care for the patients and families (Greer et al., 2013; Jacobsen et al., 2011; Kavalieratos et al., 2016; Temel, Jennifer S. et al., 2011; Temel, Jennifer S. et al.,

2010). Temel et al., described a study of early palliative care consultation that improved not only quality of life and mood, but that there was also a moderate improvement survival period in a randomised clinical trial (Temel et al., 2010). These patients received less aggressive care at the end of life as a result of the palliative care intervention. In their study, Temel et al., aimed to examine the effect of early palliative care integrated with standard oncologic care on patient-reported outcomes, the use of health services, and the quality of end-of-life care among patients with metastatic non-small-cell-lung cancer (NSCLC). Patients with metastatic NSCLC have a high burden of symptoms, with a poor quality of life and an estimated life expectancy of less than one year from the time of diagnosis. (Hopwood & Stephens, 1995; Lutz et al., 2001). Even with the advent of newer treatments, such as immunotherapy, targeted therapy and novel unconventional radiotherapy, survival gains remain poor (Roth et al., 2017). NSCLC still represents one of the major research challenges, with a high incidence and poor treatment outcomes ((Tubin et al., 2021)

Over a 3-year period, Temel et al., studied patients with newly diagnosed metastatic NSCLC, at Massachusetts Hospital, Boston, in a non-blinded, randomised controlled trial of early palliative care integrated with standard oncologic care, the intervention group, compared to standard oncologic care alone, the control group. Patients were enrolled early, within 8 weeks following diagnosis.

Guidelines for the visits were adapted from the American National Consensus Project for Quality Palliative Care. For the intervention group, the palliative care clinician focused on assessing physical and psychosocial symptoms, establishing goals of care, assisting with decision-making regarding treatment, and coordinating care according to individual patient need. The Functional Assessment of Cancer Therapy-Lung (FACT-L) scale was used to measure quality of life. This tool is well validated in patients with lung cancer, (Cella, David., 2003; Cella, David F. et al., 1995) , measuring multiple dimensions in physical, functional, emotional, and social well-being. Mood was assessed using the Hospital Anxiety and Depression Scale (HADS) and the Patient health Questionnaire-9.

Pre-treatment lower quality of life and depressed mood have been shown to be associated with shorter survival in patients with NSCLC (Maione et al., 2005; Movsas et al., 2009). It is, therefore, reasonable to associate the improved quality of life and improved mood in the palliative care intervention group, with the improved survival in this group.

A limitation to the study is the fact that it was not a blinded study. However, it would not have been possible to blind the study as it related to care rather than administration of pharmaceuticals. An important point is that this study was conducted in a well-resourced facility with comprehensive specialised palliative care services. It is unknown whether similar results would be obtained in poorly resourced environments, where education and research in palliative care are limited, as well as in situations where only home-based palliative care is available. Overall, this is an important piece of work, in an area of clinical practice with a great need for research outputs, clearly demonstrating the benefits of early integration of palliative care.

It is this seminal paper of Temel et al. that prompted ASCO to release a Provisional Clinical Opinion, recommending application of palliative care along with oncologic care in patients with newly diagnosed metastatic cancer.

However, despite this widespread support for integration of palliative care with oncologic care, and thus relief of suffering and enhancement of quality of life, palliative care referrals have been reported to occur late in the disease trajectory in many countries, including South Africa (Assi et al., 2017; Breuer et al., 2011; Lubuzo, Ginindza & Hlongwana, 2019; Sarradon-Eck et al., 2019; Vinant et al., 2017; Wentlandt, K. et al., 2012). The South African Hospice and Palliative Care Association (HPCA) reported that a 2010 study revealed that only 18% of patients needing palliative care are receiving palliative care in South Africa (South African Palliative Care Conference, 2023). Thus, the majority of patients requiring palliative care remain with poor quality of life during their illness and poor-quality end-of-life care. “The overall goal of palliative care is to improve the patient’s quality of life congruent with the patient’s preferences…….”(Kaasa et al., 2018). Below will be a brief look at the meaning of quality of life, as well as patients’ perspectives thereof.

Quality of Life

Quality of life (QOL), a core outcome of palliative care (Selman, Lucy E. et al., 2011), has been defined by the WHO as ‘an individual’s perception of their position in life, in the context of the culture and value systems in which they live and in relation to their goals, expectations,

standards and concerns" (WHOQOL, 1995). Although the WHO definition tries to encompass all dimensions, the actual meaning may be lost or missed. On the other hand, Calman's approach, published much earlier, tries to simplify the definition of QOL. According to Calman, a good QOL can be expressed as satisfaction, contentment, happiness and fulfilment and the ability to cope. To achieve this outcome, it may be necessary to reduce the gap between hope and aspirations/expectations of the individual and the actual reality or experiences of that individual, at any given moment (Calman, 1984). It may be difficult for patients diagnosed with a life-threatening condition like cancer, to express happiness and fulfilment. However, satisfaction, with their informed choices and contentment with the cancer journey as well as the ability to cope may positively impact their QOL. There is significant agreement about some of the characteristics of the QOL construct. It is widely recognised that QOL is a subjective and multidimensional experience (Kagawa-Singer, Padilla & Ashing-Giwa, 2010; O'Boyle, 1994; WHOQOL, 1995). The World Health Organization Quality of Life Assessment (WHOQOL) Group recognises this multidimensional nature of QOL to include the physical and psychological domains, level of independence, social relationships, environment and spirituality/religion/personal beliefs. Under each main domain, there may be several subdomains (WHOQOL, 1995). Any assessment of the QOL from patients depends on and is influenced by, amongst others, their physical and psychological status, for example, fatigue, pain and cognitive status.

The Eastern Cooperative Oncology Group (ECOG) performance status is used by doctors and researchers as criteria to assess how a patient's disease is progressing and how this progression is affecting the patient's activities of daily living (Oken et al., 1982). This is used to plan medical treatment and prognosis. While both these are important in the overall management of a patient, they do not address many other areas that impact quality of life, as stated above.

Patient-centred palliative care

The WHO definition of palliative care puts the patient and family at the centre of the healthcare process. There is consensus that greater patient satisfaction is an outcome of a physician consultation where a doctor gives adequate information, and where the

consultation style gives the patient enough space to express their concerns (Simpson et al., 1991). There are those who consider patient-centredness to be a complex exercise. "The concept of patient-centredness is complex, but is generally seen as an approach that emphasises, on the part of the health professional, attention to patients' psychosocial as well as physical needs, the use of psychotherapeutic behaviours to convey a sense of partnership and positive regard, and active facilitation of patients' involvement in decision-making about their care" (Mead, Bower & Hann, 2002). It should be expected that patients diagnosed with a serious illness would need a complex clinical approach in order to deal with the complexities of a serious illness. In a systematic review of patient-centred care, Giusti et al. describe that "*serious illness is especially aligned with the need for patient-centred care; the complex clinical scenarios surrounding serious illness usually necessitate the involvement of significant others and depend on high-quality communication and joint decision-making to deliver care concordant with patient preferences, with recognition and management of clinical uncertainty*" (Giusti et al., 2020). Patient involvement in their care has been associated with positive effects on patient-physician relationship, as well as on patient satisfaction (Bieber et al., 2006; Kinnersley et al., 1999). Bieber et al., in their study of patients with fibromyalgia syndrome, investigated the effects of shared decision-making (SDM) model intervention on patient-physician interaction and health outcomes. In this patient-blinded, randomized controlled study, all three arms of the study, the intervention group, the information only group, and the control group were assessed using both qualitative and quantitative methods. In the intervention group, the patients received information as in the information only group, but in addition the physicians received specific training to improve their patient-centred communication skills. Although there was no reported improvement in health outcomes after one year, there was improvement in the patient-physician relationship, as reported by both patients and doctors. There was better coping with the disease in the intervention group a year after the study commenced. These patients adopted a more positive view regarding their illness ((Bieber et al., 2006). The generalisability of this study may be limited by the selection of fibromyalgia patients, a condition that is generally poorly understood. The patients may have seemed to be responding to the intervention, because they felt supported, and had no hope of any other effective intervention. Applicability of the approach to other conditions, for example cancer, would need to be examined separately. However, coping better with the

disease may be considered as improved quality of life, as these patients can be considered as being psychologically healthier than the control group (Fagerlind et al., 2010).

Patients' Perspective on Quality of Life

Fagerlind et al. showed that in patients with rheumatoid arthritis, the understanding of the concepts of health and quality of life partially overlap and partially differ. In this case, quality of life was associated with being healthy, functioning normally, having a positive outlook on life, having a good social network and having good living conditions. While this paper tries to define this specific population's perception of quality of life, in palliative care all patients have a diagnosis of a serious illness, often progressive. Palliative care patients may, therefore, not be able to associate quality of life with being healthy. However, a positive outlook on life might correlate with alignment of the palliative care patient's outlook with the reality of a serious illness, and learning to live as best as possible, with the illness.

In a comparative study looking at perceptions of quality of life, in patients with incurable, progressive disease, receiving palliative care in South Africa and Uganda, Selman et al. studied patients with cancer and HIV (Selman et al., 2011). Using the Missoula Vitas Quality of Life Index (MVQOLI), the questionnaire covered physical, social, psychological and spiritual domains. Their findings suggest that for this type of patient, quality of life correlates best with spiritual wellbeing, highlighting the equal importance of the psychosocial and spiritual aspects of the palliative care approach. "Feeling at peace and having a sense of meaning in life were more important to patients than being active or physical comfort" (Selman et al., 2011). Looking at the different languages the questionnaires were translated into, six out seven languages were indigenous African languages, applicable to about 85% of the study population. The research population was mainly Black African and it may be that for this group, the quality of life is culturally defined, hence the strong spiritual component to their perception of quality of life. This would, however, have to be tested in a different study. This may suggest that there may be cultural determinants to referral to and acceptance of palliative care. In the case of South Africa, there is multiplicity of cultural and ethnic groups, some based on religion, some on country of origin with their own home language, for example Italian, Greek and other cultures. Even within the Black African population there are different

cultural subpopulations, for example Xhosa, Zulu, Pedi and others. It is unknown whether their perceptions of quality of life differs, and whether these perceptions would influence attitudes towards early referral to palliative care. It is, however, understandable how the researchers would have chosen mainly African research participants, as the prevalence of HIV was highest, in South Africa, in the African population, 19.9%, 3.2% and 0.5% among 15–49-year-old Blacks, Coloureds and Whites respectively (Kenyon & Zondo, 2011).

Quality of life, culture and race

With the ethnic diversity existing in South Africa, an understanding of quality of life without reference to culture and race would not be complete. Culture is often seen to be synonymous with race, often erroneously seen to be interchangeable with race and ethnicity (Kagawa-Singer et al., 2010). The Cambridge English dictionary defines culture as "a way of life, especially the general customs and beliefs, of a particular group of people, at a particular time" (Cambridge English Dictionary). "Every culture is designed to fulfil three universal needs: 1) safety and security, 2) a sense of integrity and meaning or purpose in life, and 3) a sense of belonging as an integral member of one's social network" (Kagawa-Singer et al., 2010). Culture thus becomes a significant determinant of quality of life in sickness, by its association with integrity, meaning and purpose of living, as well as safety and security. It is noteworthy that in a large survey of 9344 individuals across seven European countries, Higginson et al. looked at the participants' priorities regarding care, treatment and information, in the face of a serious illness, like cancer. The result was that most people in Italy and Spain, 57% and 81% respectively, would, in the time left, choose improved quality of life. Even more people in England and Flanders, chose QOL, with only 2% in England, to 6% in Flanders thinking extending life was most important (Higginson, Irene J. et al., 2014). From this large survey of a European community, race may not necessarily be a determinant for the choice of quality of life over extension of life. However, in international studies, when different race groups have been compared, racism has been shown to have a differential effect on availability, access and utilization of health care to individuals, and thus, their quality of life (Ellis et al., 2018; Harris, Cormack & Stanley, 2019; Kim et al., 2017).

From studies focusing on Sub-Saharan Africa, Marks & Anderson state that ".....the countries of the sub-continent provide useful comparative material because of the starkness of the

correlations between class and race, and disease patterns and health care" (Marks & Anderson, 1987). In twentieth century South Africa disease burden is differentiated according to skin colour (Marks & Anderson, 1987) and this may impact perception of QOL in patients with cancer.

Both culture and race are sensitive concepts in the South African context, because of the history of our country and its people. Coovadia et al. state that "The history of South Africa has had a pronounced effect on the health of its people and the health policy and services of the present day" (Coovadia et al., 2009).They further point out that because of the historical inheritance from colonialism which was compounded by apartheid policies of segregation and subjugation of Black people, together with failures of post-apartheid governance, South Africa's health outcomes are worse than those of many low income countries. South Africa is considered a middle-income country (Coovadia et al., 2009). In the South African context where cultural grouping often falls along racial lines, the concepts of culture and race need to be taken into account, when assessing quality of life in individuals as well as groups of people. There needs to be sensitivity to possibly culturally and racially based nuances in conversations with patients, including research participants. It is unknown whether culture or race play a role in palliative care referrals in South Africa. A patient centred approach in dealing with individual patients, irrespective of the colour of their skin, or their culture, seems to be the key in trying to enhance QOL for patients and families.

Consequences of Late Referral to Palliative Care

The World Health Organisation, in its definition of palliative care, advocates early identification and management of pain and other problems associated with serious illness, including physical, psychosocial and spiritual problems (World Health Organisation, 2002). Palliative care is applicable early in the course of the illness, in conjunction with other therapies, that are intended to prolong life (World Health Organisation, 2002). Morita et al. have suggested that late referrals to palliative care are inadequate to change the quality and delivery of care provided to patients with cancer (Morita et al., 2005). Indeed, an association between late referral to palliative care programs and negative outcomes, including deterioration in patients' QOL, receiving aggressive treatments in the few weeks before death and increased medical costs, has been found (Hirvonen, O. M. et al., 2020; Humphreys &

Harman, 2014; Michael et al., 2019). In their retrospective single centre cohort study of end-of-life (EOL) care outcomes in patients with pancreatic cancer, Michael et.al. found that out of 278 deaths, 67% were late palliative care referrals. Furthermore, the late palliative care referrals (LPCR) had 18% more emergency department presentations compared to the early palliative care referrals (EPCR), and 12.5% more acute hospital admissions. In the study by Michael et al., a total of 166 patients received chemotherapy in the last 30 days of life, of which 24.5% had LPCR, while 16.7% had EPCR. In this small Australian study, there is a clear association between LPCR and more aggressive and expensive chemotherapy at the EOL. As with all retrospective studies, the researchers here may have missed some information that would not have been in the records they used, as the data was not originally collected for research purposes. This was a single centre study, thus, limiting generalisability. However, a review of clinical trials by Davis et. al. concluded that EOL is enhanced when patients with cancer receive EPCR (Davis et al., 2015). Thus, the study by Michael et. al., although specific for pancreatic cancer patients, and involving a small number of patients, confirms the impact of late palliative care referrals versus early referral to palliative care. The length of the study, 5 years, adds strength to the findings.

In a much larger retrospective cohort study involving 943 adult cancer patients, Hirvonen et.al. investigated the impact of the duration of the palliative care period with regard to the use of hospital services and the place of death (Hirvonen et al., 2020). It is likely that a longer palliative care period would suggest an EPCR, while a shorter palliative care period would suggest a LPCR. The study, conducted in Finland, included patients with different cancer diagnoses, divided into 13 diagnosis groups. They categorised the patients into 3 groups, based on the timing of the palliative care (PC) decision. The PC decision was defined as the decision to terminate life-prolonging anti-cancer treatments and focus on symptom-centred PC. This decision was made by the oncologist responsible for that particular patient, without involving the patient (Hirvonen, Outi M. et al., 2019). The 3 groups of patients were ‘no PC decision’, ‘PC decision’, ‘PC decision and an appointment to a PC unit’. For all patients, service usage was studied 14, 30 and 60 days before death. The PC period was the time from when the PC decision was made.

Their results showed that patients with ‘no PC decision were likely to die in secondary/tertiary facilities, The earlier the PC decision was made, the more often the PC unit was visited by the

respective patients. Patients with 'no PC decision' had the highest average number of ED visits and the highest number of inpatient days, while patients with both 'PC decision and a visit to a PC unit had the lowest average ED visits and inpatient days. In summary, this research showed that patients who received 'no PC decision or very late 'PC decision, received aggressive oncologic treatments and more hospital admissions at the end-of-life, all these being considered poor quality end-of-life care (Earle et al., 2005).

Fully integrated early PC, while patients are still receiving oncologic treatment, is suggested by the WHO definition of PC. Hirvonen et al., however, investigated outcomes in patients that had already stopped all oncologic treatments, in those patients where a 'PC decision' had been made. A 'PC decision' did not necessarily equate to receiving PC.

In favour of this study is the fact that it confirmed findings of previous studies (Henson et al., 2015; Hirvonen OM et al., 2018) but also that they studied patients with many different cancer diagnoses. Thus, their results may be more representative than if they had studied a single cancer type.

According to the authors, the majority of the patients who had made contact with palliative care services died in primary care facilities. According to the authors, this was because of the small number of hospices at the time of the study. While this may be a valid reason, the authors did not explore the attitudes of the same patients towards admission and dying in a hospice. In South Africa there is generally a paucity of palliative care services, including hospices, home-based palliative care services as well as tertiary palliative healthcare facilities. The recent South African Palliative Care Conference heard that only 18% of patients requiring PC, are actually getting it (Gwyther, 2018). The reasons for this could be varied, and may include paucity of PC resources as outlined above, for example hospice facilities throughout the country, but also a number of other possible factors, like attitudes of patients/families towards PC, including hospices as well as attitudes of oncologists towards PC and hospices.

While Hirvonen et al.'s study did not look at the cost benefit in the comparative groups, it would be expected that the group with 'no PC decision' would, on average, have the highest costs. No decision had been made to stop disease modifying treatment, often costly. Indeed, a review of 38 studies by Cardona-Morrell showed that an average of 33-38% of patients near end of life, received nonbeneficial treatment, including resuscitation and admission to intensive care units (Cardona-Morrell et al., 2016). Interestingly, in the study by Hirvonen, it

is still the 'no PC group' that had more ED visits and more tertiary hospital admissions, compared to the other two groups. A reduction in hospital admissions has been shown to be economically beneficial (Huang et al., 2002), while on the other end, an active palliative care program has economic benefits, (Maetens et al., 2019), as well as quality of life benefits at the end of life (Cassel et al., 2016). Similar to international studies, DesRosiers et al. demonstrated that an outpatient palliative care service based in an urban South African hospital, reduced hospital admissions, while increasing home deaths rates (DesRosiers et al., 2014). Their study further showed a reduction in the number of admissions, length of hospital stay and hospital bed costs of about 50% per patient in the intervention group (DesRosiers et al., 2014). This important local study does not only confirm findings of international studies, but also demonstrate the feasibility and effectiveness of palliative care in a low resource setting.

The question that needs to be asked is why there is still such a lack of PC referrals in general, but especially early referrals, even with all the published evidence from international studies conducted in high-income countries. The evidence is that early PC favours patient's quality of life, while reducing costs at the same time, while late referrals impact negatively on the quality of life, as well cost of care. A review by Reid et. al. of a small number of studies from low-income and middle-income countries, concluded that low-cost palliative care was possible, that patient reported outcomes were favourable (Reid et al., 2019), thus demonstrating patient perceived improvement in quality of life. The review also concluded that palliative care was less costly than alternative treatments. This is in line with the reports from high-income countries. Below, I will take a brief look at some of the issues that have been identified by the international community.

What are the issues that potentially affect early palliative care referrals in oncology?

Patients diagnosed with metastatic cancer have physical, psychosocial and spiritual needs (Whelan et al., 1997; Whitmer et al., 2006). Palliative care is the discipline of health care that is well positioned to offer holistic multidisciplinary care that such patients need and require. The WHO advocates for early palliative care. However, in spite of existing recommendations and guidelines, as well as scientific studies supporting early palliative care,

referrals tend to occur late in the course of illness (Morita et al., 2005). Several different perspectives have emerged, as to possible barriers to early palliative care referrals. Some of these are the perception that palliative care is an alternative philosophy of care, incompatible with cancer therapy (Schenker et al., 2014); the belief that palliative care is an integral part of the oncologist's role associated with the ability to manage symptoms (Johnson, C. E. et al., 2008). In the study by Johnson et.al, 48% of specialists believed that they were well trained to offer care for symptoms in patients with advanced cancer. Twenty eight percent believed they were not adequately trained, while the remaining specialists were neutral. This is in line with the report by Salins et.al that oncologists had a sense of self efficacy to manage palliative care needs (Salins et al., 2020). The findings by Johnson et. al. and Salins et. al. raise at least two very important issues. Firstly, there seems to be a failure, by oncologists to recognise and understand the holistic nature of palliative care, beyond symptom management. In fact, according to Kaasa et.al even "symptom assessment is often not done systematically in oncology practice or not routinely incorporated into the clinical decision-making processes" (Kaasa et al., 2018). Johnson et. al., in their Australian study investigating palliative care providers' perceptions and experiences of barriers and facilitators to palliative care provision, concluded that there was failure to recognise and understand the breadth of care provided within the palliative care domain (Johnson, C. et al., 2011). Flowing from the definition of palliative care, interventions have a broad focus, and can, therefore, not be delivered by a single professional, oncology in this case, but require teams formed by multiple professionals (Kaasa et al.,2018). Thus, although oncologists agree that palliative care is an important part of cancer care, they believe they are providing palliative care whereas, as described above, they are not providing palliative care and are in fact denying their patients this care.

The second issue is the assumption that oncologists are well trained not only to understand the principles of palliative care but also to be able to apply them in looking after their patients in addition to providing oncologic care. The ESMO Taskforce on Palliative and Supportive Care reported on a survey of 895 members of ESMO from 64 countries. This survey looked at attitudes of medical oncologists towards, and their involvement in the palliative care of their patients with advanced cancer (Cherny, Nathan I. & Catane, 2003). The ESMO Designated Centres programme was set up as an incentive for the integration of oncology and palliative care at these centres. In their ESMO Taskforce survey, Cherny and

Catane showed that only about a third of the 895 respondents often collaborated with a Palliative care specialist, a palliative home-based care service, a palliative inpatient unit/hospice or a psychologist. Eighty eight percent of the respondents believed that medical oncologists should coordinate end-of-life care, and yet 42% believed they were inadequately trained for this task, this in a region where palliative care has been recognised as a specialty for a long time. In a later study, Hui et.al. surveyed 184 ESMO Designated Centres and found that 65% of these had double-qualified palliative oncologists, that is, oncologists who were also, palliative care specialists (Hui, D. et al., 2018).

In contrast, palliative care is not yet recognised as a speciality in the continent of Africa. In South Africa, in particular, only recently in 2023, the Health Professions Council approved registration of palliative care as a subspeciality. Furthermore, there has been no training of oncologists in palliative care until 2017. In their study evaluating the first palliative care training of oncology registrars Krause et.al. concluded that both registrars and their oncology supervisors were confident that the incorporation of 12-modules of palliative care training over 12 months, was both feasible and appropriate (Krause et al., 2021). This is a landmark study, as there has never been anything like it in South Africa or the rest of the African continent for that matter. The curriculum for this first palliative care training of oncology registrars in South Africa was developed from an earlier study by Krause et al. as described below.

Developing a curriculum for the training of oncologists and oncology registrars in South Africa

As stated earlier, in the work of Hui et.al, 65% of oncologists in Europe had also received training in palliative care. This could be one of the key factors affecting early referrals to palliative care services in this region. Many oncologists have reported difficulties in communicating about end-of-life matters to patients and families (Fallowfield & Jenkins, 2006; Lerman et al., 1993; Sarradon-Eck et al., 2019). This may be a reflection of poor communication skills training that most health care professionals receive (Fallowfield & Jenkins, 2006).

Globally, communication skills, pain and symptom control, teamwork and selfcare have been shown to benefit outcomes of patients, recognising them as essential attributes

required by an oncologist (Krause et al., 2018). However, in South Africa, the current curriculum for oncology registrars in training has very little emphasis on communication skills, and teamwork, amongst others (Krause et al., 2018). In their study, Krause et al. surveyed the need for palliative care training for oncology registrars in a South African setting. By means of a questionnaire, they surveyed junior and senior registrars, using an adapted validated tool developed by Cherney et al. The researchers surveyed attitude and knowledge about palliative care as well as their need for training and to develop a curriculum for the comprehensive care of patients in this group. The study also included a focus group discussion with experts that had more than 10 years of experience in oncology.

Communication skills were identified, by the experts, as extremely important competencies, all agreeing that 40% of the curriculum should focus on communication skills. Even though this was a small study, with the registrar survey limited to one university, the overall outcomes are encouraging. The study also included a FGD with participants from all 8 South African medical schools involved in the training of oncology registrars. The positive attitude of the registrar participants towards palliative care coupled with the oncology experts' perceptions of the critical need for communication skills in this area laid the foundation for strengthening patient-centred communication in the care of patients with cancer in South Africa.

It is also encouraging that Krause et. al. followed up this study, by developing a palliative care curriculum, at the University of Cape Town, for oncology registrars (Krause et al., 2021). Further encouragement comes from the fact that the first training, which was implemented as a research study, involved 5 universities in South Africa, compared to the initial survey that involved a single university.

Communication skills formed a critical part of the curriculum, constituting 40% as suggested in their first study, while pain and symptom management constituted 30% of the curriculum. Other components of the curriculum were principles of palliative care, ethical and legal aspects of end-of-life care, implementation of advance directives, bereavement and interdisciplinary teamwork, and selfcare to reduce burnout and compassion fatigue. The modules were drawn up in a collaborative effort between oncology and palliative care, as well as psychologists for the 12th module on self-care (Krause et al., 2018; Krause et al., 2021).

The course was evaluated, using the adapted Kirkpatrick triangle. The first objective of the study evaluated the oncology trainees' reaction to teaching and learning by completing anonymous online evaluations, thus "evaluating the structure of the course, the relevance of the discussion groups, the course material, and the applicability of the material in daily clinical practice" (Krause et al. 2021). The second objective determined the study participants change in knowledge and skills, using pre- and post- training MCQs after each module. The third objective determined application of palliative care knowledge and skills in oncology practice. In order to achieve this, the supervisors of the oncology trainees were interviewed.

The use of both quantitative and qualitative methods in this study adds strength as the qualitative method enabled them to pick out the "softer nuances of the impact of the course". The researchers used assessment methods that are both well-known and widely used throughout the world. However, in this study, change in organisational practice and benefit to patients were not determined. It is hoped that these important facets in the integration of palliative care and the resultant enhancement of the quality of life of patients, will be included in future studies by this group. Furthermore, while the numbers of universities and thus the participants, were small, the qualitative arm of the study produced tangible results, convincing the reader that this program may have a significant impact, in the future, in the understanding, by the oncologists, of what palliative care is and what it is not. That the skill and knowledge acquired during palliative care training is applicable early on in the care of the oncology patient, and that it is not only applicable at the end of life.

The studies by Krause et. al. sought to understand the needs of the oncologist and the oncologist trainee. However, they did not look at the needs of the patient. Below is a look at some of the needs of the patient that have been identified.

Needs of the patient

The Lancet Oncology Commission of 2018, led by Stein Kaasa stated that "Full integration of oncology and palliative care relies on the specific knowledge and skills of two modes of care: the tumour-directed approach, the main focus of which is on treating the disease; and the host-directed approach, which focuses on the patient with the disease" (Kaasa et al., 2018). The Commission further stated that in order to obtain the best outcome of patient care, the

two approaches need to be combined. In order to equip the oncologist and the palliative care clinician with specific and appropriate knowledge and skill for the successful combination of the two approaches for the benefit of the patient, an understanding of the patient's needs may become of critical value. Franks et al. (2000), further states that "the concept of need is central to the provision of health care as it defines the objectives of care and is useful in evaluating the effectiveness of health care" (Franks et al., 2000).

Murray et. al. concluded that patients with incurable cancer in developing countries have different lived experiences compared to those in developed countries (Murray et al., 2003). In their qualitative study in Scotland and Uganda, they studied the needs of patients with incurable cancer and established whether services in these countries met the patients' respective needs. The Scottish patients had unmet *psychosocial* needs despite an abundance of resources, including social workers and psychologists. Even though they had incurable cancer, radiotherapy and chemotherapy dominated their lives as they were expected to make regular visits to the hospital. But their lives were also dominated by side effects of the disease directed treatment they were still receiving, negatively impacting their quality of life.
On the other hand, the Kenyan patients, most of whom lived in abject poverty, had unmet needs in the area of *physical symptoms*. *Pain,* constant and unbearable was a lived experience for many of these patients. In addition, they suffered many of the consequences of *lack of money* at a personal level but also at the level of public institutions. But the same patients experienced peace about dying. There is no surprise in the finding of profound lack of resources in this Kenyan research population, as even in South Africa, considered to be a middle-income country, there are large areas, particularly rural areas, experiencing such profound lack of resources.
While qualitative studies are not generalisable, by their very nature, it would have thrown more light into the understanding of needs of patients, had Murray et al. interrogated further the possible reasons for the psychosocial distress in the midst of plenty amongst the Scottish patients.

A number of other studies have been published, looking at other needs of patients with cancer and other life-threatening conditions. McIlfatrick, (2007) found that all patients in the study identified the need for better care *coordination, communication* and *continuity* of care

(McIlfatrick, 2007). It is interesting that in the patients with cancer "there did not appear to be any clear demarcation in the patient journey called palliative care" McIlfatrick, (2007) They saw their journey as one continuous series of events from the time of diagnosis. Again, while this is a qualitative study and thus not generalisable, it is instructive that these patients expressed a need for continuous care instead of the oncologic care first and palliative care last model, mostly applied in this setting. This may suggest a clear need by the patient for early seamless referral to palliative care services for this type of patient. Other identified needs were: *information and choice (*as expanded on below), *social support and provision of practical care*, *psychological care*

Effective communication is a key component of palliative care. This has been recognised by oncologists and their trainees in the studies by Krause et.al. It seems to be recognised by the patients as well, as expressed in the study by McIlfatrick. "Without effective communication, there can be no adequate transfer of information, and without adequate information patients cannot make informed choices about their care. Active patient participation presupposes sufficient and relevant knowledge of the disease and treatment options. This amount of knowledge can only be reached by the continuous provision of realistic patient centred information. To provide this information, good communication skills among the oncologists and palliative care specialists are required, and the needs and wishes of patients and families need to be assessed systematically and used in the decision-making processes" (LeBlanc & Tulsky, 2011). In their multicentre qualitative study, Selman et. al. specifically looked at information needs of patients with progressive disease, and their families/caregivers in South Africa and Uganda (Selman, Lucy et al., 2009).

In their study located in 4 sites in South Africa and one site in Uganda, Selman et al. interviewed a total of 90 patients and 38 caregivers. Although the majority of the patients had HIV (54) compared to 28 cancer patients plus 6 (Dual HIV and cancer), there is no evidence that the data collected was skewed towards a particular group. Eighty five out of 90 patients mentioned *communication* and *information*, in 143 passages of text. The information needs of the patients included these main themes: 1) *causes and symptoms*; 2) *progression, treatment and management of the disease*; 3) *financial and social support*; 4) *supporting others*. Lack of information left both patients and family with important unanswered questions relating to the incurable disease. There was evidence that some of the patients

relied on the healthcare professionals to initiate and direct information giving conversations. But this was not always happening, with the healthcare professionals being busy, or being unaware or insensitive to the needs of the patients/carers.

This comprehensive study, the first of its kind in sub-Saharan Africa, through its use of qualitative methods for data collection, managed to bring to light the level of richness to the findings that a quantitative analysis would not have been able to do. It is noteworthy that all the patients were receiving palliative care. It would have been interesting if some views of their perception of palliative care had been sourced, as against the regular healthcare delivery systems they had been exposed to before palliative care referral. Whether "palliative care" as a concept was acceptable to them or whether their apparent acceptance of palliative care was in desperation, after living with unresolved symptoms and even more unmet needs, including information and communication needs, in their previous healthcare locations.

According to the Lancet Commission report on palliative care in low-income countries, palliative care and pain relief are essential elements of universal health coverage (UHC). (Knaul, 2018). There is a clear need for palliative care referrals in South Africa, as identified by both patients and clinicians. A number of factors that contribute to the low level of early palliative care referrals have been identified by the research community. However, it is unknown what factors might be affecting patient referrals in oncology, where referrals are often late or patients are admitted to die in acute hospitals. An effective way of determining the right time for referring patients needs to be established.

When is the right time to refer patients to palliative care in oncology?

According to Franks et al., understanding patient's needs is critical as the concept of need is central to defining the objectives of care, and is useful in evaluating the effectiveness of health care (Franks et al., 2000). For patients with cancer, oncologists may play the role of gatekeepers, irrespective of patient needs, negatively impacting referral of patients to palliative care. (Kars et al. 2016). Furthermore, in their systematic review of 23 studies, Salins et al., identified five themes as follows: 1) Presuppositions of oncologists and haematologists about palliative care referral; 2) Power relationships and trust issues; 3) Making a palliative care referral: a daunting task; 4) Cost-benefit of palliative care referral; 5) Strategies to facilitate palliative care referral. Some of the presuppositions associated with palliative care

referral were role conflict, loss of hope by the patient, rapture of the therapeutic alliance. One of the points raised that make a palliative care referral a daunting task is uncertainty about when to refer (Salins et al., 2020). Hui et al. have suggested a systematic symptom screening process that identifies patients with high health care needs and referring these individuals to specialist palliative care in a timely manner based on standardised referral criteria. They have named this concept "timely palliative care". (Hui et al., 2022). Timely palliative care would be personalised palliative care based on patients' needs, as against early palliative care based on disease trajectory even if patient needs were low or had been adequately addressed by the oncologist. According to Hui et al., this approach would be more beneficial due to the scarcity of palliative care resources. While this proposal has merit, it does not address the question about how oncologists understand the meaning of palliative care in the South African setting, or its benefits to patients with cancer.

An Indicator tool to guide referral of patients to palliative care

The timing to refer patients to palliative care services may not be easy to determine. Clinicians, including oncologists, often rely on their own clinical judgment to arrive at prognostic estimates (Kaasa et al., 2018). However, systematic reviews show that these estimates are frequently inaccurate and overly optimistic (Glare et al., 2003).

The Supportive and Palliative Care Indicators Tool (SPICT) was developed in the United Kingdom. It consists of general indicators that are of relevance to deteriorating patients with advanced illness, as well as disease-specific indicators for common advanced conditions, (Highet et al., 2014). This tool has been used internationally to assist health care professionals identify patients that are at risk of deteriorating and even dying and in need of specialist palliative care. The timely identification may have had a positive effect on these patients, by instituting palliative care support.

Krause et. al., through a Delphi Study, developed the modified SPICT-SA instrument (Krause et al., 2022), in line with the South African National Policy Framework and Strategy on Palliative Care that recommends the use of a simple screening tool to assist healthcare professionals to identify patients with palliative care needs that can be met by professionals from disciplines other than palliative care, thus generalist as well as specialist palliative care

(National Department of Health, 2017). The South African version has three new additional domains: trauma, infectious diseases and haematological conditions (Krause et al., 2022). The SPICT^{TM} SA, while not perfect, may be a helpful tool to clinicians, assisting them to objectively identify patients whose palliative care needs are not met, and referring such patients to palliative care services.

Summary: Several international studies and a few Sub-Saharan studies, including South African ones have confirmed the significant enhancement of quality of life in patients with cancer and their families, with early referral to palliative care services. Equally studies have demonstrated the negative effects of late referrals, not only on the patient and family, but also on the healthcare system. In low-middle income countries like South Africa, with limited resources, the effect of late referrals has a profound effect. Studies have also shown that patients with cancer have unmet needs in both the well-resourced and the under-resourced countries, impacting negatively on the quality of life of these patients and their families. With the WHO projection of increasing number of cancer deaths, year on year, especially in sub-Saharan Africa, it is important to be able to identify factors that may impede timeous referral of these needy patients to adequate palliative care services. In order to achieve the best care for patients with cancer, full integration of oncologic care and palliative care needs to occur.

Rationale for the study

The number of deaths with serious suffering in the last year of life is estimated to be 5.14 million and 6.84 million in low- and- middle- income countries, respectively, by 2060 (Sleeman et.al. 2019). South Africa is considered a middle-income country. The WHO projects a 403% increase in cancer mortalities in Africa between 2016 and 2060 (WHO 2018). These staggering projections suggest that there may be an exponential increase in suffering in patients with cancer, requiring even more palliative care efforts in the future. Even though South Africa is amongst countries that fall within Category 4a of the global palliative care atlas in 2017, that is, one category below countries where palliative care is at an advanced stage of integration

(Clark et.al. 2020), the numbers of patients receiving palliative care in South Africa are still very low at 18%, as reported at the 2023 Palliative Care Conference.

The motivation for this study has been driven, primarily, by the researcher's personal experience in the last 9-10 years, in that most of the referrals for palliative care in the private sector, come at the end of life with days to weeks of life left for the majority of referred patients. While the private sector serves a minority of patients with large financial resources compared to the public sector which serves the majority of patients with minimum financial resources, insights gained from this study, may be applicable elsewhere despite the private sector being unrepresentative of the broader South African palliative care context. The study was not designed to be representative or generalisable, but to bring out insights that may be important to explore in further research that would be more representative of the South African situation.

This study sought to determine factors influencing oncology referrals to palliative care services. What factors influence oncologists to refer patients to palliative care and what factors influence patients' acceptance of referral to palliative care services. Answers to these questions may be unique to South Africa, considering the diversity of cultures and perceptions in this population, as well as the political history of this country. However, results of international studies referred to above suggest answers to these questions could be applicable beyond the local context studied.

Research Question

Aim: To determine factors that influence referrals of patients with cancer to palliative care services.

Objectives:

1. To explore patients' experiences of palliative care services
2. To identify the triggers for patient referrals to palliative care services.
3. To explore oncologists' referral practices

Chapter Three: Methodology

Study Design:

The study was a qualitative, cross sectional research study, allowing for in-depth exploration of participants' views.

Study Sites

The study sites were two Oncology Centres and two hospices in the city of Johannesburg. These are all privately run facilities with large numbers of registered cancer patients.

Study Population

There were two study populations: 1) adult patients diagnosed with cancer, and already informed of their diagnosis; 2) medical and radiation oncologists.

Inclusion criteria:

1. Patients
- Adult patients over 21 years of age, diagnosed with cancer and receiving oncology treatment, or those who had already completed their cancer treatment.
- Participants were fluent in the English language.
- They had full capacity to give consent
2. Oncologists
- Oncologists in clinical practice for more than two years

Exclusion Criteria:

1. Patients
- Children and young adults under 21 years old
- Frail patients
2. Oncologists
- Newly qualified oncologists

Sampling

Purposive sampling was applied, selecting participants with similar characteristics required for the study (Ganca, 2018), as stated in the selection criteria above. In contrast to random sampling which aims to collect data randomly, purposive sampling is used in qualitative research to collect qualitative data from a specific population with particular characteristics. This type of sampling would provide selection of individuals who would have experience and insight into the research question, according to the aim and objectives of the study.

Sample size

The sample adequacy was determined according to qualitative research guidelines, considering what the purpose of the study was and the resources that were available for the study. A sample size of 8-14 participants was planned for each group participating in the study. According to Marshall et al., a small sample size allows more contact time and a longer interview with each interviewee (Marshall et al., 2013). The sample size enables data saturation to occur, while allowing for a deep case-oriented analysis of the data (Vasileiou et al., 2018)

Data Collection

Data Collection Tools

Interviews were conducted using semi-structured interview guides, one for each group of participants. The interview guides (Appendices 1 & 2) had been developed from the personal experience of the researcher, also drawing on published scientific literature, and in discussion with colleagues and the supervisor for this study. The interview guides had open-ended questions, allowing participants to express their subjective reality, framed by each participant's experience and context. The interview guides included probing questions to explore the topics raised in more detail, where necessary. Both interview guides were piloted with one participant per guide.

Data collection process

The researcher contacted the two oncology centres and the two Hospices telephonically, to introduce the purpose of the study and request permission to conduct the study. The clinical staff were requested to identify patients who fitted the selection criteria. In one instance the hospice doctor identified the patient and informed her. In three instances the oncologists identified the patients and informed them about the study. For the rest of the patients the professional nurse identified the patients and informed them about the study. The clinicians provided the name and contact details for participants who had agreed to take part in the study.

Data collection was done by the researcher after informed consent was obtained from each participant.

Recruitment

The data collection process was started with the recruitment of participants, after ethics approval for the study was obtained from the University of Cape Town's (UCT) Faculty of Health Sciences' Human Research Ethics Committee (HREC).

Patient recruitment

Once potential patient research participants were identified, these were then contacted telephonically by the researcher, to introduce the purpose of the study. Participants were informed of the study and given the opportunity to ask questions and to discuss with family members. It was explained that they were free to choose whether or not to take part in the research and should they decide not to take part their care would be the same and they would not be prejudiced in any way. For those participants that agreed to take part in the study, a face-to-face follow-up session with the researcher was arranged. This session was for giving full information about the study, and obtaining informed consent from those participants who were willing and available to participate. An interview date and time, and place convenient to the participant, was arranged. The interview process was preceded by the signing of informed consent (Appendix 3 & 4) by those participants agreeing to be enrolled for the study.

Oncologist recruitment

A total of ten oncologists were identified as potential research participants, according to the selection criteria. Nine of these were approached individually, telephonically. One oncologist was not approached as he was travelling abroad for an extended period of time. Of the nine oncologists approached, eight were interviewed. The 9th oncologist was not included in the study as there was no response to follow-up. The purpose of the study was introduced telephonically by the researcher, followed by face-to-face session with the researcher to give full information on the study. They were given the opportunity to ask questions, and time to make their decisions whether to participate in the study or not. Informed consent was obtained before the commencement of the interview process. An interview date and time, and place convenient to the oncologist participant was arranged.

Conducting the interviews

The interviews were conducted, using the English language, by the researcher with either the patient or the oncologist, allowing her to spend time in the field, and interact with the participants, as they explored their reality. (Cresswell, 2013). In qualitative research, there is a need to enter the research setting with the necessary care, engaging with the research participant in an open and empathic manner, with minimal disturbance to the natural setting (Kelly, 2014). The English language was chosen as these study sites are located in areas where the patients are fluent in the English language. The researcher conducted a face-to-face interview with each participant, ensuring anonymity and confidentiality of each participant at all times by not linking names to the interview recordings and transcripts. At the beginning of the interview the researcher introduced herself and the aims of the project. The process of what would happen, how the interview would be conducted and approximately how long it might take, was explained. It was also explained what would happen to the data, ensuring confidentiality at all times. The participants were assured that there were no right or wrong answers, that the interview was about their personal experiences, and that it could be stopped at any time if the participant so wished. The researcher then ascertained whether the participant understood the aims of the study, and still wished to continue with the interview. An opportunity to ask questions was offered to the participant.

Audio recordings of all interviews were made, after consent was obtained from each participant. The interviews ranged from 8 to 45 minutes. The audio recordings were backed up with a second audio recorder. In addition to these recordings, special remarks, critical incidents, facial expressions and other body language were captured in writing by the researcher. The audio recordings were transcribed, verbatim, by the researcher.

Data storage and confidentiality

The audio recordings, the transcripts and all written material were stored in a locked cabinet, in the office of the researcher. Only the researcher carried the key and had access to the research material, thus ensuring confidentiality. Any subsequent public dissemination of the research study findings will not carry the identity of the research participants. Electronic data is stored on a password protected computer.

The audio recordings will be destroyed after the closure of the study, as they have all been transcribed. The transcripts will be retained for a period of five years as they may be used as a basis for a follow-up study

Data analysis

The recorded interviews were transcribed verbatim by the researcher.

Thematic analysis was conducted manually by the researcher with the support of the supervisor, and themes derived from the words of the participants. Patterns were recognised, examined and recorded on paper. In order to achieve this, the following steps were followed:

Familiarisation, immersion and themes

In order to establish familiarisation with the data, the researcher started transcribing and reading the text, immediately after the first interview. By immersion, the data was read and reread repeatedly by the researcher until the researcher knew the details and nuances of the data. The researcher became familiar enough with the interview transcripts to know where particular text and data occurred in the transcript. The researcher was then able to identify the organising principles that 'naturally' underlay the text. Themes and subthemes were identified.

Coding

Coding of the text went hand-in-hand with induction of the themes. This involved rereading of the text by the researcher followed by marking off relevant sections of the text with different coloured pens, identifying text material that belonged to specific themes that were being identified. Similar coloured text sections were then transferred onto blank pieces of paper and given relevant headings describing the identified content. This process resulted in breaking down of the text into separate meaningful pieces, that were later clustered together under themes and subthemes.

Elaboration

The emergent themes were explored more closely, in constant discussion with the researcher's supervisor, in order to identify the finer nuances of meaning of the codes and themes, until there were no further significant new insights. The process of elaboration involved elaborate comparison and analysis of the pieces of data to identify data most suitable to each theme. It was important for the researcher to be aware of any personal biases in the interpretation of the data

Ethical Considerations

The study was commenced, only once approval was obtained from the UCT HREC, and permission received from management of the research sites. The researcher ensured that the research participants' rights, safety and well-being were protected. The patient participants (PP), being cancer patients, were vulnerable members of society, with a life-threatening illness. In addition, they were persons that were highly dependent on medical care. As a clinician with formal training in Palliative Medicine, the researcher was able to treat these participants with compassion and empathy, ensuring that there was no coercion of participants to agree to give consent to participate in the study.

There was ongoing evaluation of continued capacity to make autonomous informed choices by individual patient participants, even as the study was underway. The researcher also made sure that consent from this group was not influenced by expectation of preferential treatment or fear of disapproval or retaliation (Terre Blanche & Durrheim, 2014). A distress protocol that

was made available for participants experiencing distress during interviews was not used, as no-one exhibited distress.

Chapter Four: Results

Introduction

This study sought to explore factors that influence referral to palliative care services in oncology. Specifically, the study explored factors that influence patients to accept referral to palliative care services, as well as factors that influence oncologists to refer their patients to palliative care services.

A total of twelve patients were interviewed. Eleven had been diagnosed at least two years prior to the interview, with a range of 2-6 years since diagnosis. One patient had been recently diagnosed, two months before the interview. However, he had had two previous cancers, both of which were in remission. The demographics of the patient participants are shown in Table 1.

Table 1. Patient Participants

Patient	Gender	Age (years)	Cancer Type	Time since diagnosis (years)
1	M	82	Prostate	3
2	F	72	Ovary	2
3	F	40	Cervix	2
4	M	81	Bladder	2
5	M	71	Multiple Myeloma	0.5
6	F	63	Endometrial	3.5
7	F	60	Mouth	2
8	F	50	Breast	4
9	F	63	Kidney	2
10	F	60	Breast	6
11	F	62	Kidney	9
12	F	67	Breast	10

A total of eight oncologists were interviewed. All had been working as oncologists for more than two years, ranging from 4–39 years. Table 2, below shows the demographics of the oncologists.

Table 2. Oncologist Participants

Participant	Gender	Age	Time practising as oncologist (years)
1	F	55	21
2	F	68	39
3	F	38	4
4	M	52	20
5	M	55	18
6	F	38	9
7	F	48	10
8	M	53	17

Results

The results were analysed into five main themes.

The first theme dealt with experiences of care as seen by patients. The second theme dealt with the relationship between oncology and palliative care. The third theme dealt with patient views on referral to palliative care services. The fourth theme dealt with triggers for referral to palliative care services. The fifth theme dealt with practical issues to be considered when referring to palliative care services.

See table 3 below

Table 3: Thematic Analysis

Theme One	Theme Two	Theme Three	Theme Four	Theme Five
1. Experiences of Care	**2.Relationship between oncology and palliative care**	**3.Patient views on referral to palliative care services**	**4.Triggers for referral to palliative care services**	**5.Practical considerations in referral to palliative care services**
1.1. Communication with palliative care services	2.1 Palliative care as a parallel and sequential discipline	3.1 Preference for early referral to palliative care services	4.1 Patient perceptions of triggers for referral 4.1.1 Pain & other symptoms 4.1.2 Metastatic disease 4.1.3 Psycho-social symptoms 4.1.4 family need	5.1 Availability and capacity of palliative care services
1.2 Communication with oncology services	2.2 Palliative care as an integral part of the continuum of care in oncology	3.2 Uncertainty regarding referral	4.2 Oncologist perceptions of triggers for referral 4.2.1 Pain and other symptoms 4.2.2 Repeated hospital admissions	5.2 Oncologists' views of patient perceptions of palliative care and hospice services
1.3 Patient experiences with palliative care services	2.3 Palliative care as end-of- life care	3.3 Preference for oncologist's opinion vs palliative care team opinion		5.3 Cost of palliative care
1.4 Patient experiences with oncology services				5.4 Lack of desire to work as a team
				5.5 Need for training of oncologists

Theme One: Experiences of care

1.1 Communication with palliative care services

All twelve patient participants (PP) had favourable experiences with palliative care services, including hospices. Palliative care services offered better communication to both patient and family, compared to the other specialists, including oncologists.

"T*he most helpful thing is being able to talk to you. I think you can get people to talk, you know.....just get them to open up". [PP5]*

"*We feel communication was much better with the palliative care services outside of the hospital than was the case with the five specialists within the hospital".* [PP4]

1.2 Communication with oncology services

None of the oncologists interviewed raised communication with their patients as an issue.

One out of twelve patient participants expressed satisfaction, that the oncologist had communicated well with her. The patient participant felt the oncologist had explained everything to her and her family.

"*The cancer was back again. So, I had another session of oncology (chemotherapy) and in each case the oncology (chemotherapy) was quite clearly explained to me, what would happen, how I would cope with it, what problems I might have". [PP2]*

The majority of patient participants reported unfavourable experiences of communication with their oncologists. These experiences ranged from minimal information to an overload of information, without giving the patient enough time to assimilate and make informed decisions.

The participants felt that sometimes there was too little information, and sometimes too much medical information which was overwhelming.

"*When I was diagnosed, I was in **extreme shock**.....I had to force the doctors to care for me, to tell me more. They were not telling me enough, I think either because they were too scared or they were too ehh, not really, they felt sorry. I think that when a doctor knows a person has been newly diagnosed, **they must sit with the patient, draw pictures, show them, go slow, go slow, don't rush up because the patient has just been delivered a death sentence. And now what? Communication, preparation, compassion, all these".*** [PP7]

"Now the talks are getting to that angle that I need to do a total hysterectomy. I felt like I'm still young. I didn't understand when the doctor said 'your womb is looking good'. Then why do I need to do a total hysterectomy?. Then it was a Wednesday, I said to the doctor please give me some time so that I can go and process this thing. She said 'I'm going to book you in for a total hysterectomy on Monday; I'm going to cut you from the throat, going down, remove

your womb. You might have a bag permanently, the pooh bag, and you might leak'….so she sold me the scary part of the whole thing". [PP3]

The patients were not informed about palliative care services or when they were, the information was not comprehensive and, if palliative care was mentioned, the information was given late when they were approaching end of life.

"I think doctors (oncologists) are a bit careless in the way they just tell you these things and ehhm when they speak about your stages and palliative care……because I didn't know stage 4 until I went for a second opinion, and you know, it was quite a ***shock*** *then. Ehh , that was hard for me". [PP8]*

"Now what I got from the….oncology centre was that 'you need a blood transfusion'. And although it was arranged by them, we didn't quite know exactly what it's at. I feel they have a little bit neglected stressing enough how much you people (palliative care services) will mean to, not just to me, but to the whole family that we have here. It means a lot to me. But I think a great lot to my daughter and her husband, and they know that I'm being looked after in a proper way". [PP11]

1.3 *P*atient experiences with palliative care

All twelve patient participants were appreciative of the palliative care services they had been referred to. They felt the palliative care services provided excellent service not only to the patient, but to the family and caregiver, providing a much needed safety net. The counselling helped in coming to terms with the diagnosis of cancer, and coping with it.

Palliative care services, it's been brilliant so far, really brilliant. I am very very glad that I was given the opportunity to register with hospice almost straight away, three and a half years ago and built up a fantastic relationship [PP6].

"Yes, with the counselling to come to terms with the cancer and facing it. Also, then the support my family got was excellent. They included all of them, even my daughter in Australia, and it helped them cope" [PP9]

1.4 Patient experiences with oncology services

Eleven out of twelve patient participants had unfavourable experiences with their oncologists. The participants felt oncologists lacked compassion and empathy and found this quite hurtful.

"…….and then again when I was in hospital with this brachial plexus, where they confirmed it… my doctor, he wasn't all that compassionate; he could have been a lot more compassionate…., just general compassion in sharing bad news. When the doctor came, he said ehhm, 'from now it's ***JUST PALLIATIVE!****' It sounded like it was over, you know….downhill. There was one visit where he like, as I walked out, he was like '****It's all over you, this is it****'. And that was* ***QUITE HURTFUL****! [PP8]*

"Dr (oncologist) is well known in the field, and one has to put your trust in him. But it gives you a feeling of well, but does he really care enough to read the notes? Out in a nutshell, there seems to be very very little empathy". [PP5]

The following patient was about to be discharged home without the involvement of a palliative care team.

*"I mean Dr (oncologist) wanted to send me home and said to me, my husband must just put a plank on the stairs, get a mattress and get two guys from the street to help lift me up and get me into my bed.****.I mean hee!*** *I had so much pain, I couldn't walk" [PP9]*

The participant below felt bombarded with instructions about what the medical staff wanted to do with her, with no consideration of how she felt and with disregard of what symptoms she was experiencing and needing help with at the time.

"Absolutely. I feel that their decisions were made for me…..you ***have to go*** *for a blood transfusion, you* ***have to be here on that day, at this time.*** *It will take about 3 hours. I ended up lying there for 6 hours in excruciating pain! [PP11]*

The following patient explained how she had found her care, overwhelming, without full explanation.

"Well, I found it to be very overwhelming. I came to peace when I went to hospice. …You were bombarded with do this, do that, do the other, and they didn't say you're not going to have a positive outcome…because the tumour is too big…..At no time did they help with explanation". [PP9]

Theme Two: Relationship between oncology and palliative care

All eight oncologist participants saw a relationship between oncology and palliative care. However, there was a marked difference in how they defined this relationship. Some saw palliative care as a parallel discipline, some a collaborative discipline, part of oncology, while yet others saw it as a discipline to refer to at the end of life.

2.1 Palliative care as a parallel service

One oncologist believed there needed to be a separation between oncologic care and palliative care

"So, I do think……., there's definitely a line between the two". [OP6]

One oncologist felt that while palliative care is a part of oncology, it was also a separate discipline on its own.

"Well, it forms part of oncology, but it's also, you know, a separate entity on its own..." [OP6].

2.2 Palliative care as an integral part of *the continuum of care in* oncology

Three oncologists felt that palliative care was an integral part of the continuum of care in oncology, was much more holistic and was not end of life care

"I just think it's an integral part of continuation of care. It's an integral part of oncologic care. I don't necessarily equate palliative care to terminal care. Although it (terminal care) is a part of palliative care, it is not the end all and be all of palliative care, as against hospice which tends to be terminal care". [OP4]

"*I think the relationship is better instituted earlier rather than later, if possible, and I think for me palliative care has a much holistic approach compared to the oncologist which is much more focussed. There is a continuum, so there's a continuum, I think. So, I think palliative care is not just the end of life, but it's from the beginning of a terminal illness that potentially has an end of life". [OP1]*

One oncologist thought there should be a collaborative relationship between oncology and palliative care.

"So, it's most certainly should be intertwined, and they should complement each other. So, I think oncology and palliative care should really be intertwined. The two disciplines should be working together". [OP3]

2.3 Palliative care *as* end-of-life *care*

Two oncologist participants put emphasis on the role/relevance of palliative care at the end of life.

*"Well, it forms part of oncology, but it's also, you know, a separate entity on its own. So definitely it's where you, in oncology you decide that you cannot cure a patient and you have to look at the quality of life as your main call for that patient…….**that end-of-life care is very important for the patient physically as well as emotionally and spiritually as well……that they can have quality that last couple of days'**. [OP6]*

*"I mean there's definitely a relationship because at some stage, depending on the cancer you have, patients will need palliative care, **especially at the end of life"**. [OP5]*

Theme Three: Patient views on referral to palliative care services

3.1 Preference for early referral to palliative care services

Seven patient participants expressed a need for early referral to palliative care, in order to allow for: awareness of the availability of palliative care services, making of informed choices, building of relationships and trust with and getting the support of the palliative care team.

"I think I should have been referred to palliative care services at the time I was diagnosed. Maybe then I would have chosen not to go to the oncologist, but to see the palliative care person first, and then be allowed to make my decision which way I want to go. Once there is a diagnosis, the different members that can potentially look after me, the patient, can meet with me, then I make the decision which way I want to go". [PP11]

*"Maybe there should be awareness before you reach that horrible stage 4, you know, more awareness of hospice services and that (palliative care services), so that it's not a thing that only happens at stage 4. It's so scary. At least **to be aware** of ehh palliative care services and that. To walk with you, **and again**, to be aware that these services **are** available. Ehm you*

know; so that …, it's not sort of somewhere you go only when something horrible happens, you know. When the final horrible, horrible things happen". [PP8]

3.2 Uncertainty regarding referral to palliative care services

Two patients were uncertain about early referral to palliative care.

One patient participant did not think it was necessary to refer early unless there was physical pain.

"I think ehhh…the pain, well, I think unless there's pain. The palliative care is very good but is it necessary?'. [PP4]

Another patient felt an early referral in the absence of pain symptoms would be a sign that she was dying.

"When my oncologist said 'I'm now referring you to….palliative care doctor…. I felt like, oh are you tired of me now? Are you getting rid of me now? Am I not curable? Why am I now seeing a doctor at home? It's like this doctor will see me until I die. ***So, I'm dying"****. [PP3]*

3.3 Preference for oncologist's opinion vs palliative care team opinion

One patient participant saw a palliative care referral as a kind of back-up to the oncology services. This patient had just recently been referred to palliative care services, involving a doctor and a hospice nursing sister. The oncology team were treating her for partial bowel obstruction, as an outpatient. She was on total parenteral nutrition (TPN) and intravenous (IV) medication at home. The husband had been trained to administer the TPN as well as the medication. She was no longer on disease directed treatment. She and her husband placed high value on these treatments, not wanting to explore alternative palliative care protocols for home-based care. Although she was happy with the arrival of the palliative care team, she was clear that if she had to choose who to follow in terms of treatment options, she would choose the oncologist team approach.

> *"……it's that kind of back-up that gives a bit more confidence for when things are going rough……and a clash? If it did happen (between oncologist and palliative care services), I guess in my mind, a clash would mean the oncologist would* ***NOT*** *move aside, I would listen to what the oncologist was saying". [PP2]*

Theme Four: Triggers for referral to palliative care *services*

4.1 Patient perceptions

All patient participants expressed satisfaction with palliative care services on symptom management. Interestingly the most frequently mentioned symptom was pain, physical pain. They saw the onset of pain as an important trigger for referral to palliative care services

Four patients thought that the diagnosis of cancer should trigger a referral to palliative care services.

"I think they should tell you the option, give you the option, right when you're diagnosed and tell you you've got cancer". [PP9]

One patient participant could not think of a specific trigger, but still felt that the opportunity, the diagnosis of cancer, should be used to find out more about palliative care services.

"Ehh, I can't think of a specific trigger, but like I said before, people should use the opportunity to register with hospice, to find out as much as they can about palliative care for themselves, from the beginning, right from the beginning, so that they are able to make informed choices and decisions". [PP6]

4.1.1 Pain and other symptoms

Three patients expressed that physical pain should be a trigger for referral to palliative care services.

"I think the pain thing would trigger from a patient perspective but maybe the patient's doctor – the oncologist" [PP2]

"I think, ehh, the pain, the pain that I had. I don't know if doctors (oncology team) knew what it was about, because they said it (the cancer) was clear, and the next thing I've got this terrible pain. So, it was a good thing that (palliative care services) came into my life". [PP4]

One patient felt that there should be an holistic approach that supports any patient that is not coping.

"I just think if you're not coping, even with pain, any symptom, like a holistic approach. I mean you can have any symptom. You don't always get the benefit you need from your doctors, oncologists. You can't get hold of them". [PP10]

4.1.2 Metastatic disease

One patient felt that the diagnosis of metastatic disease should trigger a referral to palliative care services

"Jaa, yes, when it's spread. I've had cancer three times…..so I kinda feel that I'm a little bit experienced in this, in this whole business. But for somebody who certainly, ehh, is told you've got cancer and it's spread somewhere else, he needs a lot of support". [PP5]

4.1.*3* Psychosocial symptoms

One patient participant mentioned the need to speak to someone.

"….where you need to speak to someone, you need a doctor almost every day or maybe once a week, and you have palliative care doctor who is on call 24 hours per day". [P3]

4.*1.4* Family symptoms

The patient participants expressed a belief that both patients and their families would benefit from referral to palliative care services. They spoke about the suffering of their families as a result of the diagnosis of cancer in one family member. The suffering is from the time of diagnosis, through treatment and the period when all disease-directed treatment has been stopped. The counselling services that form part of palliative care services were seen to be of great help to not only patients, but also to family members.

"But as soon as a person gets diagnosed with cancer, the whole family gets diagnosed, the whole family gets cancer……!! Everyone gets affected". [PP3]

One patient participant who had had cancer three times, thought he was more emotionally accepting of his situation, compared to those who were being diagnosed for the first time. After observing a close friend, whose husband had been recently diagnosed with cancer, he expressed his feeling that psychosocial support needs to be immediate for both patient and family.

"This morning, I spoke to a lady whose husband in January went for his appendix op. They found that on his one kidney he had a growth. But they only took it out about three weeks ago. ……..but for her in the three weeks, you can't imagine how stressed this poor lady is., and for me this is where you (palliative care services) come in". [PP5]

One patient participant felt his wife had benefitted from palliative care referral.

I think (wife) has benefitted a million times from the referral letter. Since we were sent to (palliative care services (wife) has been very relaxed, knowing she could get (palliative care services). She is very happy". [PP4]

The one patient participant that had not been referred to palliative care services believed that all patients should be referred to palliative care services.

"I think it will be good (to refer) because then you will get counselling for the whole family, earlier on, because often I find, even with me, it's not so much me as a patient, it's the people around (me)……They are the ones who suffer. It is a big psychological side. They absorb a lot of things….They're carrying all that stuff like carrying a time bomb. My daughter……she has been having panic attacks since I was diagnosed". [PP10]

4.*2* Oncologist Perceptions

All eight oncologists had opinions about when to refer patients to palliative care services. Some opinions were based on the needs of the patients, as determined/perceived by the oncologist, while some were based on how the oncologist felt. Some still based the decision on how the patient felt.

One oncologist participant thought the referral should happen before the onset of deterioration in performance status.

"The referral needs to happen before (deterioration in performance status)! For example, if you treated a patient for a brain tumour, okay, and you finished all treatment and you (oncologist) tell the patient if you have a problem, contact me. But then there are other things that happen. When do I stop the steroids? or should I?…..oh I forgot to stop them, or it's actually finished (the steroids)! So, I think, in a way, it's unfair on the patient to up and down, up and down for everything when somebody who works in palliative care can maintain a close contact with the patient". [OP 2]

Two oncologists thought that referral to palliative care services should happen when either the patient or the doctor feel the patient or the doctor is not coping.

"*Whenever, whenever the patient or the doctor feel that they're not getting everything, they can optimise their situation. Sometimes a patient coming to see me 3 or 4 times in a month*

because of side effects of treatment OR complications of disease OR problem with what they are having is not being addressed, then I think it's a perfect avenue (palliative care referral). Both admissions and consultations at the rooms, literally, being here every week, that is fear. Anxiety. So, I mean, if you see at home, then she is also calmer and it improves the quality of her life". [OP4]

"I think when both maybe I'm not coping and the patient is not coping. Maybe that's a good palliative care referral. And I'm not sure that I take adequate care of their, for instance, of spiritual needs....."[OP1]

One oncologist thought that referrals should happen for those who are receptive

"I think as early as possible for those who are receptive. So, in patients who need any sort of support, to be honest with you. Like I said earlier, it's not just patients who are terminal who need support, and that can be someone with early breast cancer who is divorced and a single mom, working two jobs, and she doesn't know how she is going to get all her treatments. That's the kind of person who might need that support". [OP3]

4.2.1 Pain and other symptoms

Two oncologist participants thought the emergence of physical symptoms should trigger a referral to palliative care.

"Obviously, we look at the ECOG status of the patient, how they cope; if it's getting worse, their pain. Is it getting more and more?". [OP5]

"Well, pain and other things like anxiety. All these things, sometimes, cannot be managed just in a once a month setting (by the oncologist). Sometimes they need two, three or four times per month. And so, it's difficult for me". [OP4]

4.2.2 Repeat admissions

Oncologist thought that repeat admissions should trigger a referral to palliative care

"*Say if they are really battling, with repeated hospital admissions" [OP6]*

Theme Five: Practical issues to be considered when referring to palliative care services

5.1 Availability and capacity of palliative care services

Four oncologist participants felt that it would be ideal to refer early, but didn't think there was enough palliative care capacity/availability

"*I don't think it's a bad thing, but I don't think there's capacity for that….laughing… You see an ideal situation, in an ideal situation, sure, but I don't think there's capacity. I don't think there's enough of you. There isn't! It's not ready for prime time".* [OP4]

"I'll tell you the truth, I'll tell you the truth. Probably the most important, ehh, ehh, aspect. Do I have someone to refer to… So, the first thing is availability and the ***skill*** *of the person or facility, that can deal with the problems of that specific patient".* [OP2]

Two oncologist participants believed that the area where the patient lives causes a hindrance to referral to palliative care services

"So, once the support team (palliative care team) has been assembled, it depends on which area you, (the patient) lives in. That's a big problem in South Africa. Some areas are well catered for, while others are very poorly catered for". [OP8]

"*I have tried getting hold of the hospice in Tembisa, (an African township), and I have phoned numerous times…..and I've heard they closed down. So, I deal specifically with (name) hospice, and they've told me they don't go to Tembisa".* [OP7]

5.2 *Oncologists' views of patient p*erception of palliative care and hospice services

Two oncologist participants thought the perception that palliative care was end-of-life needs to be changed.

"*But like, again, we need to change the perception of palliative care, that metastatic disease does not mean end-of-life….But I think it's a good idea but we don't do it, and it's a very good idea".* [OP1]

"I think, I think, I think you have to discuss it (palliative care referral) with the patient, and I really.., and you know one of the big problems is that this word 'palliative' because I think the patients think about palliative is to die; the doctor is not going to do anything. They are just going to let me, they are just going to let me die". [OP2]

One oncologist participant felt some people had a negative perception about hospice

"*…Some people have got a very negative idea about hospice. So, they think if you go there you're going to die. They don't understand why we do it, we want him to get the help".* [OP5]

Two oncologist participants expressed patient preference in regard to referral to palliative care as a major consideration.

"I think the biggest not to refer is if they (patients) do not want a referral". [OP1]

"Largely, eh, patients' ehmm, requests or patient preferences is a large determinant,

because if a patient doesn't want palliative care, then we can't refer to palliative care".

[OP3]

5.*3* Cost of palliative care

Three oncologist participants thought that cost may deter patients from accepting palliative care referrals

"I think one of the other issues is always cost. Patients always want to know what are the costs, what is going to be the out-of-pocket costs? I think that is very important for patients to know". [OP3]

"Financial need, if the medical aids cannot authorise (palliative care) and the patient needs to pay and do not have the money……..you would rather look at admitting patient to the ward". [OP6]

5.*4* Lack of desire to work as a team

One oncologist participant saw as a problem, to early palliative care referral, the involvement of more than the oncologist in the care of the patient.

"I want to see those patients myself*…. So, I feel that as soon as I cannot do anything anymore for the patient, then we go through to the palliative approach. Yes, you (palliative care services) can, maybe, give them pamphlets, advice, things like that, but I think that if too many doctors are involved in a patient becomes confusing sometimes in the patients".* [OP6]

5.5 Need for training of oncologists

One oncologist expressed the need for oncologists to be trained, including herself.

"I think that we as physicians that refer to palliative, we should be trained, trained or educated, or whatever word it is, how to do it, how to do it, you know! .....I think that, in a way, we have to be educated..." [OP2]

Summary*:* The qualitative interviews with a total of 20 participants, twelve patients and eight oncologists, brought out a wealth of information. The qualitative data was coded into five main themes as follows: 1) Experience of care, 2) Relationship between oncology and palliative care, 3) Patient views on referral to palliative care services, 4) Triggers for referral to palliative care services, 5) Practical issues to be considered when referring to palliative care services

A discussion of the qualitative findings of this study follows in the next chapter.

Chapter Five: Discussion

On reflecting on the interviews with patients and with oncologists, the lack of congruency between the oncologists' statements and the patients' perceptions and statements was striking..

In the patients' reports on experience of care, all twelve patients expressed satisfaction with palliative care services, including hospices. With regard to communication, eleven patients reported unfavourable experiences of communication with their oncologists. These experiences ranged from minimal information to an overload of information, without giving the patient enough time to assimilate and make informed decisions. According to Giusti et al., this type of patient experience is not consistent with patient-centred care that is required in serious illness, that depends on high quality communication and joint decision-making (Giusti et al., 2020). In both studies by Krause et al. and by McIlfatrick, effective communication was recognised as a key component of palliative care (Krause et al., 2018; McIlfatrick, 2007).

Patients were not informed about palliative care services, and where they were, information was not enough and was near the patient's end of life. However, all twelve patients felt they had received excellent care from the palliative care services, while on the contrary, eleven out of twelve patient had unfavourable experiences with their oncologists. They felt that oncologists lacked compassion and empathy and found this quite hurtful. These unfavourable

experiences may be in line with published literature, that many oncologists have reported difficulties in communicating about end of life matters to patients and families ((Fallowfield & Jenkins, 2006; Lerman et al., 1993; Sarradon-Eck et al., 2019).

Communication experiences of patients

All twelve patients reported that palliative care services, including hospices, provided better communication to both patient and family, compared to all the specialists, including oncologists. This is not a surprising finding as palliative care training includes communication as one of the core skills of palliative care. Patients spoke of how the diagnosis of cancer was a great shock and how it felt like a death sentence. They also spoke about how the oncologists lacked compassion and empathy at a time when they needed such the most, delivering bad news in a cruel manner. This, again emphasises how palliative care training equips the clinician with special knowledge and a set of skills that enable those trained in palliative care to be empathic and to be able to deliver bad news in a compassionate way. Oncologists in South Africa have not received such training until recently (Krause et al., 2021). And certainly, the oncologists who participated in this study had not received any palliative care training. In fact, one of the oncologists reported that she had never met a palliative care physician before, although she had referred some patients to hospice before. This may be as a result of the low number of qualified palliative care clinicians, but also perhaps, that those that are qualified in palliative care have not made themselves visible enough, as, for example, attending and presenting at oncology conferences.

Information needs of patients

As stated by LeBlanc and Tulsky, “Without effective communication, there can be no adequate transfer of information, and without adequate information patients cannot make informed choices about their care.

Active patient participation presupposes sufficient and relevant knowledge of the disease and treatment options. This amount of knowledge can only be reached by the continuous provision of realistic patient centred information. To provide this information, good communication skills among the oncologists and palliative care specialists are required, and the needs and wishes of patients and families need to be assessed systematically and

used in the decision-making processes" (LeBlanc & Tulsky, 2011). From the statement above, it is to be expected that many of the information needs of the patients in this study would not be met. Indeed, eleven out of twelve patients reported unmet information needs. There was either too little information or too much information which left patients confused and anxious. As a result, most of the patients felt decisions were made for them, by the oncologists, without understanding of patient preferences. This may be due to a lack of a systematic and comprehensive assessment of patient and family needs. This is in line with the Lancet Commission Report (Kaasa et al.,) that "symptom assessment is often not done systematically in oncology practice or not routinely incorporated into the clinical decision-making processes"(Kaasa et al., 2018). These symptoms could be physical, psychosocial or spiritual. The patients were not informed about palliative care services or when they were, the information was not comprehensive and, was given late when they were approaching end of life. One patient was confident that had she been given enough information about palliative care, early enough, she would have opted to not have oncologic treatment. The outcome was that these patients were in emotional distress for not having participated in shaping their own cancer journey. It is to be noted that only one oncology practice had a social worker as part of the team. However, this social worker did not actually counsel patients and families. Her time was largely taken up by filling forms to register patients on palliative care programs of their medical aids. She would also be filling out other forms required by patients, for example for disability grants and insurance payouts. The lack of provision of psychosocial support to patients and their families in oncology practices speaks to the poor understanding of the need for and application of systematic and comprehensive assessment of patient symptoms in oncology practices, as stated above by Kaasa et al.

Although there was anger and emotional distress in ten of the patients, once they realised that they had not been given enough information to enable them to make informed decisions, none of them had actually confronted the oncologists. This may be due to a belief that they, the patients, are dependent on the oncologist for any possible cure of the cancer (Hillen et al., 2012), however remote this possibility may be, and therefore, didn't want to upset them. Another possibility is that with a life-threatening illness like cancer, patients are overwhelmed by the diagnosis and lose their sense of agency (Parvan, 2015)

Oncologists' perception of their own understanding of communication with patients

Many oncologists, in international studies, have reported difficulties in communicating about end-of-life matters to patients and families (Fallowfield & Jenkins, 2006; Lerman et al., 1993; Sarradon-Eck et al., 2019), and this may be a reflection of poor communication skills training. In this study, none of the oncologists reported any difficulties in communicating with their patients. This may be as a result of their own lack of awareness of the importance of the need for effective communication in the face of life-threatening illness, as patients reported dissatisfaction with oncologists' communication. The lack of awareness is likely to be as a result of the omission of the communication skills training during oncology training. However, this point was not probed further in this study.

Appreciation of Palliative Care by patients

The patients reported late referral to palliative care, except for one patient, and had not been given enough information about palliative care by the oncologists. But even in this setting, in this study, all twelve patients expressed high appreciation of the palliative care they had received.

"The overall goal of palliative care is to improve the patient's quality of life congruent with the patient's preferences" (Kaasa et al., 2018), with quality of life being considered a core outcome of palliative care (Selman et al., 2011). The high appreciation may therefore, suggest that these patients had perceived enhancement of their quality of life as a result of the referral to palliative care. The appreciation was not only for themselves but also for their families and caregivers. The service helped them come to terms with the diagnosis of cancer and cope with it. This is in line with the definition of palliative care by the WHO, where care to address distressing symptoms that are physical, emotional and spiritual, is offered to patient as well as to family. This finding also confirms what several other published studies have already found, that palliative care impacts positively on quality of life, with an increase in satisfaction in patients and family (Temel et al., 2010; Temel et al., 2011; Jacobsen et al., 2011; Kavaliaretos et al., 2016; Greer et al., 2013). In fact, this finding that all twelve patients were highly appreciative of palliative care goes against the perception, by oncologists, that patients may not be receptive to referral to palliative care services. This perception by oncologists will be discussed further, later in this chapter.

The majority of patients, seven patients, expressed a need for early palliative care referral, in order to allow for: awareness of the availability of palliative care services, making of informed choices, building of relationships and trust with and getting the support of the palliative care team. One patient felt that a palliative care referral was not necessary unless there was physical pain, while another patient felt that a referral to palliative care services suggested death was imminent. Yet another patient saw palliative care referral as a kind of back-up to the oncology services. If she had to choose between oncology and palliative care services, she would choose oncology services even though she was no longer receiving disease directed treatment.

Understanding the meaning of palliative care

According to the patients, they were not given comprehensive information, by the oncologists, about palliative care and this information often came quite late when they were nearing the end of their lives. But all twelve patients had a positive understanding of palliative care, once they experienced it. They understood palliative care as being comprehensive and holistic, providing for both patient and family. In other words, even these late referrals were still seen as being beneficial and impacting quality of life of both patient and family. One can extrapolate from this, that early referral would even be more beneficial, as has been shown in previous studies. One patient, in this study, was an exception, in that she had an early referral to hospice three and a half years earlier. This patient's perception was that her whole family, including a daughter, who lived in a far-off country, had had great benefit from this early referral. One patient seemed to be unclear what palliative care is. The patient claimed to be 'happy with the oncologist ..... and the other doctors at the hospital' as everything had been explained to her and yet, she had deep existential issues. This was the patient that was on TPN as described earlier. Of note is that there was no evidence of bowel obstruction at the time of the interview. She was asking herself what the meaning of her life was and she felt that it had no meaning. At the time of making this statement, during the interview, she had the look of someone who felt lost and all alone. This was contradictory as she had earlier expressed satisfaction with the oncologist's 'palliative care plan' which included the TPN feeding and IV medication, plus admission to hospital as needed. Again, as stated earlier, this patient had recently been referred to a palliative care physician and a palliative care professional nurse, but had had no previous referral for psychosocial support, for which she had great need as

described above. Both the physician and the nurse had just started seeing her, and were about to refer her to the counsellor who was a member of this team. This lack of psychosocial support demonstrates the lack of understanding of the comprehensive, holistic nature of comprehensive patient care, by the oncologists. The oncologist put high value on inappropriate modalities of IV treatments, thus influencing the patient and family to also put high value on these treatments in place of evidence-based, less costly palliative care protocols that are appropriate for this kind of patient, especially for home-based care. Of note is that this patient died from sepsis due to the central venous line. Although there was only one patient out of twelve, who understood palliative care to be what the oncologist and the hospital doctors ordered, it is important to note that there may be a group of patients and families that believe more in the 'palliative care approach' of the oncologist and hospital clinicians, who, themselves, would not have received any training in palliative care.

One of the possible reasons the oncologists in this study did not give enough information about palliative care may be that they do not understand what palliative care is. Notably, one oncologist believed that patients needed to be referred early, before distressing symptoms emerged. This same oncologist was the only one that expressed the need for oncologists to be trained in palliative care. For the rest of the oncologists, their lack of perceived need for training in palliative care, may be in line with the findings of Salins et al. about a sense of self efficacy amongst oncologists (Salins et al., 2020). Thus, although oncologists agree that palliative care is an important part of cancer care, they believe they are providing palliative care whereas, as described above, they are not providing palliative care and are in fact denying their patients this care, thus causing much distress to patients and their families. In this study patients showed much distress.

Understanding the relationship between oncology and palliative care

All eight oncologists saw a relationship between oncology and palliative care but differed in how they defined this relationship. Some saw palliative care as a parallel/sequential discipline, some a collaborative discipline, part of oncology, while yet others saw it as a discipline to refer to at the end of life.

The Lancet Commission report, led by Stein Kaasa and published in 2018 maintains that full integration of oncology and palliative care is dependent on knowledge and skill embedded in

oncologic tumour-directed care and a palliative care host-directed approach (Kaasa et al., 2018). These seem to be parallel approaches, each discipline having its own focus. The Commission recognises that full integration is necessary in order to achieve best outcome for the patient and family. This would be achieved by combining these two approaches. Oncologists, in this study expressed different views about the relationship between oncology and palliative care. Indeed, some saw them as parallel discipline as reported in the Commission report. One oncologist put it this way ".....there's definitely a line between the two". This approach, as stated in the Commission report, is unable to bring the best outcome for the patient and family. The approach does not take into account the needs of the 'host' of the cancer, the patient. This may be as a result of failure of the education system to elevate the necessity for recognition and satisfaction of the needs of the patient as being paramount in achieving best outcome for the patient. Franks et al. state that the concept of need is central to defining the objectives of care and is useful in evaluating the effectiveness of health care (Franks et al., 2000).

Interestingly, a number of oncologists expressed a need for collaboration between oncology and palliative care, and as such, a need for early referral to palliative care. However, these statements are not matched by current practice in South Africa as referrals to palliative care occur when patients are nearing end of life. There could be several reasons for this as stated by some of the oncologists, such as availability of qualified palliative clinicians, cost of palliative care, location of patients in areas deemed to be inaccessible to palliative care teams because of distance or perception of danger, such as Black African townships. But there may also be a more fundamental reason for this contradiction between expressed belief and actions. Oncologists, not trained in palliative care, may not have the full understanding of the principles of palliative care and how implementation of these principles, over and above oncologic care or in some instances, in place of oncologic care, actually makes a difference in the quality of life of patients and their families. Patients expressed how palliative care helped the patients and their families not only to accept the diagnosis of cancer, but also to cope with it. The study by McIlfatrick found that all patients preferred better continuity of care, amongst other findings. They saw their patient journey as a continuous series of events, from the time of diagnosis and expressed a need for continuous care instead of the oncologic care first and palliative care last model mostly applied (McIlfatrick, 2007). This finding of need for continuity

of care, as well as the finding in our study that palliative care helped patients not only to cope with the cancer, but also to accept the diagnosis, seems to suggest that early introduction of palliative care is preferred and is beneficial to patients with cancer

Awareness and understanding of the unmet needs of the South African oncology patient is necessary to both oncologist and palliative care clinician, for successful integration of oncology and palliative care. Such understanding may result in collaborative advocacy at national level, for provision of adequate resources for early palliative care referral and care. It may also influence curriculum reform and revision in the training of both palliative care clinicians as well as oncologists.

Perceptions of triggers for referral to palliative care

All patients recognised onset of symptoms, especially physical pain, as a trigger for referral to palliative care. They expressed satisfaction in how their symptoms were better dealt with by palliative care clinicians, than by the oncologists. Beyond physical pain they expressed need for referral to palliative care services for psychosocial symptoms for the patient and to deal with the suffering their families experienced as a result of the diagnosis of cancer. Patients further recognised the emergence of metastatic disease, even before onset of symptoms, to be a reason for referral to palliative care services. All twelve patients had experienced palliative care and understood what it meant.

Some of the patients felt that the diagnosis of cancer on its own should be a trigger for referral. Because of the holistic nature of palliative care, a referral to palliative care was seen as necessary for patients that were not coping, for the benefit of both the patient and family. They spoke about the suffering of their families as a result of the diagnosis of cancer in one family member, reporting that the suffering is from the time of diagnosis, through treatment and the period when all disease-directed treatment has been stopped.

On the other hand, the oncologists' perception of referral for palliative care differed amongst themselves. Some opinions were based on the needs of the patients, as perceived by the oncologist, while some were based on how the oncologist felt. Some still based the decision on how the patient felt, whether the patient felt like being referred to palliative care. It was also mentioned that referral should happen to those who are receptive to such referral.

Palliative care referrals could be appropriate in situations of psychosocial need, even in the early days of the disease trajectory. Lastly, some of the oncologist referred specifically to physical pain as well as other worsening symptoms to trigger referral to palliative care, as well as those patients that are repeatedly admitted to hospital.

On the whole, the oncologists felt that referrals should depend on how the oncologist perceived the patient's needs. This approach meant the oncologist, alone, made the decision without involvement of the patient, and as described above, the oncologists have not explored patient preferences for care. This is contrary to patient-centred care and contrary to the evidence-based view that serious illness requires patient-centred care (Giusti et al., 2020), and that greater patient satisfaction is achieved where the patient is given enough space to express themselves, regarding their illness (Simpson et al., 1991). The complex clinical scenarios that manifest in serious illness may not be manageable by one person and one approach, and thus need a team approach that includes the patient as a key member of the team. A team approach is one of the fundamental principles of palliative care, which, unfortunately, was not an approach practised by the oncologists. One oncologist thought that referral to palliative care services should happen when either the patient or the doctor feels the patient or the doctor is not coping as in being unable to control physical symptoms. The issue of not coping by the patient was associated with possible fear, anxiety felt by the patient. This could be an expression of unmet psychosocial and spiritual needs. This approach misses the principle of prevention of distressing symptoms, seeking adequate palliative care support before onset of the symptoms. One oncologist felt that referrals should be done for those patients that are receptive to palliative care. The discussion above emphasises the number of deficiencies in understanding of palliative care by oncologists. In light of this problematic understanding of the concept of palliative care by oncologists, it is unlikely that their introduction of the topic to patients would be accurate. As such, the perceived non-receptiveness of these patients to such referral may not be a true reflection of the patient's understanding, view and thus rejection of palliative care, but may be a projection of the oncologists' limited and possibly negative view of palliative care.

Practical considerations in referral to palliative care.

A number of oncologists, while agreeing that there is a need for early referral, were concerned about the limited availability/capacity of palliative care services. To emphasise this point, one oncologist stated that she had never met a palliative care doctor until the meeting with the researcher. In line with availability, was the specific South African situation of unequal distribution of resources, with townships having even less availability of palliative care services. Unfortunately, the researcher did not probe further, whether the oncologists had tried to make contact for assistance and build a relationship with the Association of Palliative Care Services or the Association of Palliative Care Practitioners of South Africa (Palprac).

Further concerns were raised about the need to change the perception that palliative care was end of life care. Associated with this, was the expressed negative perception about hospice as a place where people go to die. Some oncologists reported the need to take into account, as a major consideration, patient preferences. From this study where patients highly appreciated palliative care, and preferred early referral to palliative care, it would seem that the view that palliative care was end of life, may not be the patients' view but that of oncologists. This may be the oncologists' perception, projected onto the patients. Furthermore, there was no clear evidence from the data, that oncologists fully explored patient preferences.

A further consideration raised by the oncologists was that of possible out of pocket costs for the patient referred to palliative care services when medical aid schemes made no provision for palliative care in their programs. In such instances the oncologist might look at admitting the patient to the ward. However, there has been an increase in medical aid coverage for palliative care over the last few years. Although cost of palliative care is only one factor contributing to paucity of referrals to palliative care, It is hoped that this provision will contribute to some increase in referrals in the private sector.

Another view from one oncologist was that involvement of more than one doctor, in the care of the patient, may confuse the patient. This oncologist could not see a collaborative effort, as a team. It may be true that a patient seen by a number of clinicians where there is no effective communication, where there is poor care coordination and no team approach, may be confused. However, the team approach is one of the key principles of palliative care, and

its effectiveness is backed by scientific evidence. As Giusti et al. suggested the complexities of serious illness, such as is the case in patients with advanced cancer, require the involvement of significant others, high quality communication and joint decision making (Giusti et al., 2020). The oncologist that does not want to work with others, works against these fundamental principles required in order to deliver patient-centred care.

Lastly, training of oncologists referring to palliative care services was seen as being necessary in order to assist the oncologist in understanding the palliative care referral process. Patients in this study, including the one patient who made contradictory statements about being happy with the oncologist and the hospital doctors, while at the same time articulating that life was meaningless, all had unmet needs. They had the full range of distressing symptoms at the time they were referred to palliative care services. Even though they had been given the best care by the palliative care teams, the emotional pain they had suffered while still with the oncologists, was evident. The inability for oncologists to provide patient-centred care to patients with cancer, and their families has been recognised internationally for a long time. This recognition was not just by the palliative care clinicians, but also by the oncologists themselves. ESMO, back in 1999, with the formation of a Palliative Care Working Group in order to improve palliative and supportive care of patients with cancer, by the oncologists, has seen major improvements in the standard of care for these patients (Cherny, N. et al., 2010). An earlier study by Cherny et al. reported that 88% of oncologists believed they should handle end-of life conversations with their patients. However, 47% of oncologists believed they didn't have adequate training for such work (Cherny, Nathan I. & Catane, 2003). In this study the oncologists were not asked if they believed they had enough knowledge and skill to effectively integrate oncology and palliative care in the care of their patients, as suggested by Kaasa et al (Kaasa et al., 2018). However, the evidence we have from the study suggests that oncologists may have neither knowledge nor skill to apply principles of palliative care in their practices. A further concern is that they may not even be aware of this deficiency, nor the need to put the patient at the centre of the conversation about their care, as stated by the patients. A two-pronged approach may be worth considering in the South African situation where government may not make much of a contribution to change the current situation, in spite of stated intentions. A training program, such as the one evaluated by Krause et al., that is designed to help oncology registrars acquire the knowledge and skills necessary for integration of

palliative care and oncology, for the benefit of the patient and family (Krause et al., 2021), needs to be strengthened as laid out in the recommendations below. It is interesting to note that the study done by Hui et al., 15 years after the study by Cherny et al., reported that 65% of the oncologists at the designated ESMO centres, had also qualified as palliative care specialists (Hui, D. et al., 2018). Such progress is unlikely to happen overnight, and it is unlikely to happen without a clear sustained program. In other words, while the study evaluated by Krause et al. is a good start, there needs to be another level of training, that may help sustain the process of change (Harrington, Voehl & Voehl, 2015).

Limitations of the study

One of the limitations of this study was about unasked questions. Some of these probing questions were thought of, by the researcher, after the patients had died. The other area that could have been probed further, with the oncologists, was that of communication.

Another limitation was that of possible bias in the case of the researcher, as the researcher is a practising medical doctor, a palliative care trained clinician who has experienced late referrals to palliative care. The researcher was aware of this possible bias and tried to be as objective as possible in the analysis of the data, with the help of the supervisor who has large experience in conducting qualitative studies.

Lastly, the impact of race and culture was not explored in this study, even though South Africa is well known for its racist past and the effects of racism and culture on healthcare.

Chapter Six: Conclusion and recommendations

The purpose of this study was to explore factors that influence referrals of patients with cancer to palliative care services. The study met the objectives of exploring patients' experience of care, the triggers for palliative care referral in the study setting and oncologists' referral to palliative care.

The study brought in-depth exploration of the participants' views. These views provided insights into some of the issues affecting early referral to palliative care in oncology. The inclusion of both patients and oncologists, in the study, added value to the results of the study. The following conclusions have been made:

Patients had unmet needs regarding effective communication from oncologists, whose approach lacked empathy and compassion, and was hurtful. As such, they had unmet needs regarding information about palliative care as well as oncologic care. This inhibited their ability to participate in shared decision-making, resulting in patients being recipients of non-patient-centered care.

Palliative care was acceptable to these patients with advanced cancer, and they were highly appreciative of the palliative care received from palliative care services, including hospices. Thus, palliative care may be acceptable to patients with advanced cancer. Patients advocated for early palliative care referral to help them with physical and other symptoms. They advocated for early palliative care in patients with pain and other symptoms, and when there is metastatic disease where they could be helped, together with their families, to accept the diagnosis of cancer and help them to cope with the illness and the consequences of the illness.

According to the oncologists, issues of availability of qualified palliative care clinicians, cost of palliative care, location of the patient especially those in Black African townships, need to be considered when referring patients to palliative care services.

Oncologists seem to place low value to the psychosocial needs of patients as none of the oncology practices used the services of a social worker or counsellor for emotional support of the patient and family

Oncologists may not be aware of their need for training in palliative care as only one of them expressed the need for oncologists to be trained in palliative care. Furthermore, none of the oncologists raised the issue of lack of effective communication with patients, again suggesting that they may be considering themselves as being well qualified, with effective communication skills.

In summary, patients with advanced cancer remain with unmet needs, without or very late referral to palliative care, and thus with poor quality of life. Palliative care training of oncologists may change their understanding of the meaning of palliative care and its role in the management of these patients, thus impacting positively on the patients' quality of life.

Recommendations

1. The South African government signed up to Resolution WHA67.19 of 2014 of the World Health Assembly that stated the need to create or strengthen palliative care as part of the continuum of care. Furthermore, the Policy Framework and Strategy for Palliative Care in South Africa requires mandatory palliative care training for all health professionals. From this study there is evidence of lack of understanding of the principles of palliative care amongst oncologists. The following recommendations are, therefore, made

    - Palliative care should be a required part of oncology registrar training, as has been initiated in 5 medical schools.
    - To negotiate with the Health Professions Council of South Africa to make palliative care part of the continuing medical education requirements, for qualified oncologists in the first phase and for other clinicians at a later date.

2. One of the points raised by oncologists was the lack of availability of qualified palliative care clinicians to refer oncology patients to in both the private and the public sector. The postgraduate diploma in palliative care (PG DIP Pall Med), offered by the University of Cape Town (UCT), is well regarded. A problem that has been raised by potential students to this program, is cost. The following recommendations are made:
    - An increased recruitment of new students to register for this program be made through the active participation of full members of the Association of Palliative Care Practitioners of South Africa (Palprac)
    - Engagement of medical aid schemes by Palprac be initiated for partial or full funding of some of such new recruits to encourage enrollment for the UCT Post Graduate Diploma in Palliative Medicine.

3. There seems to be poor visibility of palliative care clinicians, with one oncologist stating that she had never met a palliative care clinician until the interview for this study. One way of improving visibility is to present credible evidence of the impact of palliative care on patients' quality of life. The following recommendations are made:

- Through Palprac, palliative care clinicians be encouraged to engage in research in order to produce evidence that can be published and possibly lead to evidence-based practice in oncologic and palliative care. An effort to make the a collaborative project between palliative care clinicians and oncologist, may help with integrating of palliative care and oncology
- Further engagement by Palprac with medical aid schemes for funding of such research, as schemes stand to benefit even more from research that confirms the reduction of cost of care effect of palliative care.

4. For full integration of the oncologic care 'tumour approach' and the palliative care 'host approach', there is a need for palliative care clinicians to have conversations with oncologists while strengthening oncology registrar palliative care training. The following recommendation is made:
    - Palprac formally engages with the oncology organizations operating in South Africa, such as the Icon oncology network, SAOC and SACO

5. As a direct follow-up to this study, the following research projects are recommended
    - An investigation of the understanding and perceptions of effective communication by oncologists in South Africa
    - An investigation of ways to effectively raise public awareness of palliative care

References

American Cancer Society. *Cancer Facts & Figures* 2019. Atlanta: American Cancer Society 2019. Accessed on 22 March 2020

Assi, T., El Rassy, E., Ibrahim, T., Moussa, T., Tohme, A., El Karak, F., Farhat, F., Faddoul, S. et al. 2017. The role of palliative care in the last month of life in elderly cancer patients. *Supportive care in cancer.* 25(2):599-605. DOI:10.1007/s00520-016-3444-3.

Back, A.L., Young, J.P., McCown, E., Engelberg, R.A., Vig, E.K., Reinke, L.F., Wenrich, M.D., McGrath, B.B. et al. 2009. Patient, Caregiver, Nurse, and Physician Perspectives: Loss of Continuity and Lack of Closure. *Arch Intern Med.* 169(5):474-479. DOI:10.1001/archinternmed.2008.583.

Bieber, C., Muller, K.G., Blumenstiel, K., Schneider, A., Richter, A., Wilke, S., Hartmann, M. & Eich, W. 2006. Long-term effects of a shared decision-making intervention on physician-patient interaction and outcome in fibromyalgia. A qualitative and quantitative 1 year follow-up of a randomized controlled trial. *Patient Educ Couns.* 63(3):357-366. DOI:10.1016/j.pec.2006.05.003.

Blanchard, C.G. 1997. The Crisis of Cancer: Psychological Impact on Family Caregivers. *Oncology.* 11(2):189-194.

Bradley, C. 2019. Economic Burden Associated with Cancer Caregiving. *Seminars in Oncology Nursing.* 35:333-336.

Breuer, B., Fleishman, S.B., Cruciani, R.A. & Portenoy, R.K. 2011. Medical Oncologists' Attitudes and Practice in Cancer Pain Management: A National Survey. *Journal of clinical oncology.* 29(36):4769-4775. DOI:10.1200/JCO.2011.35.0561.

Calman, K.C. 1984. Quality of life in cancer patients - an hypothesis. *Journal of medical ethics.* 10:124-127.

Cambridge English Dictionary. Definition of Culture. https://dictionary.cambridge.org/dictionary/english/culture, accessed 9 February 2023.

Cardona-Morrell, M., Kim, J., Turner, R.M., Anstey, M., Mitchell, I.A. & Hillman, K. 2016. Non-beneficial treatments in hospital at the end of life: a systematic review on extent of the problem. *Int J Qual Health Care.* 28(4):456-469. DOI:10.1093/intqhc/mzw060.

Cassel, B.J., Kerr, K.M., McClish, D.K., Skoro, N., Johnson, S., Wanke, C. & Hoefer, D. 2016. Effect of a home-based palliative care program on healthcare use and costs. *Journal of the American Geriatrics Society.* 64(11):2288-2295.

Cella, D. 2003. Impact of ZD1839 on non-small lung cancer-related symptoms as measured by the functional assessment of cancer therapy-lung scale. *Seminars in Oncology* 30(1):39-48.

Cella, D.F., Bonomi, A.E., Lloyda, S.R., Tulsky, D.S., Kaplan, E. & Bonomi, P. 1995. Reliability and validity of the Functional Assessment of Cancer Therapy - Lung (FACT-L) quality of life instrument *. *Lung Cancer.* 12:199-220.

Cherny, N., Catane, R., Schrijvers, D., Kloke, M. & Strasser, F. 2010. European Society for Medical Oncology (ESMO) Program for the integration of oncology and Palliative Care: a 5-year review of the Designated Centers' incentive program. *Ann Oncol.* 21(2):362-369. DOI:10.1093/annonc/mdp318.

Cherny, N.I. & Catane, R. 2003. Attitudes of medical oncologists toward palliative care for patients with advanced and incurable cancer. *Cancer.* 98(11):2502-2510. DOI:10.1002/cncr.11815.

Coovadia, H., Jewkes, R., Barron, P., Sanders, D. & McIntyre, D. 2009. The health and health system of South Africa: historical roots of current public health challenges. *Lancet.* 374:817-834.

Cresswell, J., 2013 Qualitative Inquiry & Research Design Choosing among five approaches.

Davis, M.P., Temel, J.S., Balboni, T. & Glare, P. 2015. A review of the trials which examine early integration of outpatient and home palliative care for patients with serious illnesses. *Ann Palliat Med.* 4(3):99-121. DOI:10,3978/j.issn.2224-5820.2015.04.04.

DesRosiers, T., Cupido, C., Pitout, E., van Niekerk, L., Badri, M., Gwyther, L. & Harding, R. 2014. A hospital-based palliative care service for patients with advanced organ failure in Sub-Saharan Africa reduces admissions and increases home death rates *Journal of Pain and Symptom Management.* 47(4):786-792.

Dunlop, R.J., Davies, R.J. & Hockley, J.M. 1989. Preferred versus actual place of death: A hospital palliative care support team experience. *Palliat Med.* 3:197-201.

Earle, C.C., Neville, B.A., Landrum, M.B., Souza, J.M., Weeks, J.C., Block, S.D., Grunfeld, E., & Ayanian, J.Z. 2005. Evaluating claims-based indicators of the intensity of end-of-life cancer care. Internatitional Journal for Quality in Health Care. 17(6): 505-509.

Ellis, L., Canchola, A.J., Spiegel, D., Ladabaum, U., Haile, R. & Gomez, S.L. 2018. Racial and Ethnic Disparities in Cancer Survival: The Contribution of Tumor, Sociodemographic, Institutional, and Neighborhood Characteristics. *J Clin Oncol.* 36(1):25-33. DOI:10.1200/JCO.2017.74.2049.

Fagerlind, H., Ring, L., Brulde, B., Feltelius, N. & Lindblad, A.K. 2010. Patients' understanding of the concepts of health and quality of life. *Patient Educ Couns.* 78(1):104-110. DOI:10.1016/j.pec.2009.05.016.

Fallowfield, L. & Jenkins, V. 2006. Current Concepts of Communication Skills Training in Oncology *Recent Results in Cancer Research.* , 5168:105-112.

Fereidouni, A., Rassouli, M., Salesi, M., Ashrafizadeh, H., Amir Vahedian-Azimi, A. & Salman Barasteh, S. 2021. Preferred Place of Death in Adult Cancer Patients: A Systematic Review and Meta-Analysis. *Frontiers in Psychology.* 12. DOI:10.3389/fpsyg.2021.704590.

Ferlay, J., Colombet, M., Soerjomataram, I., Mathers, C., Parkin, D.M., Piñeros, M., Znaor, A. & Bray, F. 2019. Estimating the global cancer incidence and mortality in 2018: GLOBOCAN sources and methods *International Journal of Cancer.* 144, 1941–1953 (2019:1941-1953.

Filipek, A. 2020. Family as a fundamental social unit shaping security culture: Polish realities. *Security & Defense Quarterly.* 30. DOI:http://doi.org/10.35467/sdq/125778.

Florea, S.V. 2022. The Family - A Fundamental Institution of Society (Abs).

Franks, P.J., Salisbury, C., Bosanquet, N., Wilkinson, E.K., Kite, S., Naysmith, A. & Higginson, I., J. 2000. The level of need for palliative care: a systematic review of the literature. *Palliat Med.* 14:93-104.

Ganca, L. 2018. *Purposive Sampling.* University of Cape Town.

Giusti, A., Nkhoma, K., Petrus, R., Petersen, I., Gwyther, L., Farrant, L., Venkatapuram, S. & Harding, R. 2020. The empirical evidence underpinning the concept and practice of person-centred care for serious illness: a systematic review. *BMJ Glob Health.* 5(12). DOI:10.1136/bmjgh-2020-003330.

Glare, P., Virik, K., Jones, M., Hudson, M., Eychmuller, S., Simes, J. & Christakis, N. 2003. A systematic review of physicians' survival predictions in terminally ill cancer patients. *BMJ.* 327:195.

Grassi, L. & Rosti, G. 1996. Psychosocial Morbidity and Adjustment to Illness Among Long-Term Cancer Survivors. *Psychosomatics.* 37:523-532.

Greer, J.A., Jackson, V.A., Meier, D.E. & Temel, J.S. 2013. Early Integration of Palliative Care Services with Standard Oncology Care for Patients with Advanced Cancer. *CA Cancer J Clin.* 63:349-362.

Gwyther, E. 2018. How is Palliative Care part of the Right to Health? The South African Evidence.

Harrington, H.J., Voehl, F. & Voehl, C.F. 2015. *Model for Sustainable Change: PMI White Paper*.

Harris, R.B., Cormack, D.M. & Stanley, J. 2019. Experience of racism and associations with unmet need and healthcare satisfaction: the 2011/12 adult New Zealand Survey. *Aust NZ J Public Health.* 43:75-80. DOI:10.1111/1753-6405. 12835.

Henson, L.A., Gao, W., Higginson, I.J., Smith, M., Davies, J.M., Ellis-Smith, C., Daveson, B.A., . & . 2015. Emergency department attendance by patients with cancer in their last month of life: a systematic review and meta-analysis. *Journal of clinical oncology.* 33(4):370-376.

Higginson, I.J. & G. J. A. Sen-Gupta, G.J.A. 2000. Place of care in advanced cancer. A qualitative systemic literature review of patient preferences. *J Palliat Med.* 3(3):287-300.

Higginson, I.J., Gomes, B., Calanzani, N., Gao, W., Bausewein, C., Daveson, B.A., Deliens, L., Ferreira, P.L. et al. 2014. Priorities for treatment, care and information if faced with serious illness: A comparative population-based survey in seven European countries. *Palliat Med.* 28(2):101-110.

Highet, G., Crawford, D., Murray, S.A. & Boyd, K. 2014. Development and evaluation of the Supportive and Palliative Care Indicators Tool (SPICT): a mixed-methods study. *BMJ Support Palliat Care.* 4(3):285-290. DOI:10.1136/bmjspcare-2013-000488.

Hillen, M.A., Onderwater, A.T., van Zwieten, M.C.B., de Haes, H.C.J.M. & Smets, E.M.A. 2012. Disentangling cancer patients' trust in their oncologist: a qualitative study. *Psycho-Oncology.* 21:392-399.

Hirvonen, O.M., Leskela, R.-L., Gronholm, L., Haltia, O., Rissanen, A., Tyynela-Korhonen, K., Rahko, E.K., Lehto, J.T. et al. 2019. Assessing the utilization of the decision to implement a palliative goal for the treatment of cancer patients during the last year of life at Helsinki University Hospital: a historic cohort study. *Acta Oncologica.* 58(12):1699-1705.

Hirvonen, O.M., Leskela, R.L., Gronholm, L., Haltia, O., Voltti, S., Tyynela-Korhonen, K., Rahko, E.K., Lehto, J.T. et al. 2020. The impact of the duration of the palliative care period on cancer patients with regard to the use of hospital services and the place of death: a retrospective cohort study. *BMC Palliat Care.* 19(1):37. DOI:10.1186/s12904-020-00547-8.

Hirvonen OM, A.J., Syrjänen KJ, Jyrkkiö SM. End-of-life decision, emergency, g.t.p.c.o.c.p.v., BMC, d.i.S.W.F.a.r.c.s. & 2018;17:128., P.C. 2018. End-of-life decision guiding the palliative care of cancer patients visiting emergency department in South Western Finland: a retrospective cohort study. *BMC Palliat Care.* 17:128.

Hopwood, P. & Stephens, R.J. 1995. Symptoms at presentation for treatment in patients with lung cancer: implications for the evaluation of palliative treatment. *British Journal of Cancer.* 71:633-636.

Hui, D., Cherny, N.I., Wu, J., Liu, D., Latino, N.J. & Strasser, F. 2018. Indicators of integration at ESMO Designated Centres of Integrated Oncology and Palliative Care. *ESMO Open.* 3(5):e000372. DOI:10.1136/esmoopen-2018-000372.

Hui, D., Elsayem, A., De La Cruz, M., Berger, A., Zhukovsky, D.S., Palla, S., Evans, A., Fadul, N. et al. 2010. Availability and Integration of Palliative Care at US Cancer Centers. *JAMA.* 303(11):1054-1061.

Hui, D., Heung, Y., Bruera, E. 2022. Timely Palliative Care: Personalizing the Process of Referral. Cancers. 14, 1047. https://doi.org/10.3390/cancers14041047

Humphreys, J. & Harman, S. 2014. Late referral to palliative care consultation service: length of stay and in-hospital mortality outcomes. *The Journal of Community and Supportive Oncology.* 12:129-136. DOI:10, 12788/jcso.0034.

IARC. 2023. Estimated number of new cases from 2020 to 2040, Both sexes, age 0-85+. Cancer Tomorrow. https://gco.iarc.who.int/tomorrow, accessed 16 May 2023.

Illingworth, N., Forbat, L., Hubbard, G. & Kearney, N. 2010. The importance of relationships in the experience of cancer: a re-working of the policy ideal of the whole-systems approach. *Eur J Oncol Nurs.* 14(1):23-28. DOI:10.1016/j.ejon.2009.06.006.

Jacobsen, J., Jackson, V., Dahlin, C., Greer, J., Perez-Cruz, P., Billings, J.A., Pirl, W. & Temel, J. 2011. Components of early outpatient palliative care consultation in patients with metastatic nonsmall cell lung cancer. *J Palliat Med.* 14(4):459-464. DOI:10.1089/jpm.2010.0382.

Johnson, C., Girgis, A., Paul, C., Currow, D.C., Adams, J. & Aranda, S. 2011. Australian palliative care providers' perceptions and experiences of the barriers and facilitators to palliative care provision. *Support Care Cancer.* 19(3):343-351. DOI:10.1007/s00520-010-0822-0.

Johnson, C.E., Girgis, A., Paul, C.L. & Currow, D.C. 2008. Cancer specialists' palliative care referral practices and perceptions: results of a national survey. *Palliat Med.* 22(1):51-57. DOI:10.1177/0269216307085181.

Kaasa, S., Loge, J.H., Aapro, M., Albreht, T., Anderson, R., Bruera, E., Brunelli, C., Caraceni, A. et al. 2018. Integration of oncology and palliative care: a Lancet Oncology Commission. *Lancet Oncol.* 19(11):e588-e653. DOI:10.1016/S1470-2045(18)30415-7.

Kagawa-Singer, M., Padilla, G.V. & Ashing-Giwa, K. 2010. Health-related quality of life and culture. *Semin Oncol Nurs.* 26(1):59-67. DOI:10.1016/j.soncn.2009.11.008.

Kars, M.C., van Thiel, G.J., van der Graaf, R., Moors, M., de Graeff, A., van Delden, J.J. 2016. A systematic review of reasons for gatekeeping in palliative care research. Palliat Med. 30(6):533-48

Kavalieratos, D., Corbelli, J., Zhang, D., Dionne-Odom, J.N., Ernecoff, N.C., Hanmer, J., Hoydich, Z.P., Ikejiani, D.Z. et al. 2016. Association Between Palliative Care and Patient and Caregiver Outcomes: A Systematic Review and Meta-analysis. *JAMA.* 316(20):2104-2114. DOI:10.1001/jama.2016.16840.

Kelly, K. 2014. From encounter to text: Collecting data in qualitative research. In *Research In Practice: Applied Methods for the Social Sciences.* D.K. Terre Blanche M, Painter D, Ed.: University of Cape Town Press(Pty) Ltd.

Kenyon, C. & Zondo, S. 2011. Why do some South African ethnic groups have very high HIV rates and others not? *African Journal of AIDS Research.* 10(1):51-62.

Kim, A., Ashman, P., Ward-Peterson, M., Lozano, J.M. & Barengo, N.C. 2017. Racial disparities in cancer-related survival in patients with squamous cell carcinoma of the esophagus in the US between 1973 and 2013. *PLoS One.* 12(8):e0183782. DOI:10.1371/journal.pone.0183782.

Kinnersley, P., Stott, N., Peters, T.J. & Harvey, I. 1999. The patient-centredness of consultations and outcome in primary care. *British Journal of General Practice.* 49:711-716.

Knaul, F.M. 2018. Integrating palliative care into health systems is essential to achieve Universal Health Coverage. *Lancet Oncol.* 19(11):e566-e567. DOI:10.1016/S1470-2045(18)30600-4.

Krause, R., Parkes, J., Gwyther, E., Anderson, D. & Hartman, N. 2018. Building a Palliative Care Curriculum for Oncologists. *The Specialist Forum.* 18 (4):42-43.

Krause, R., Parkes, J., Hartman, N., Anderson, D. & Gwyther, L. 2021. Evaluating palliative care training in the oncology registrar programme in South Africa. *African Journal of Health Professions Education.* 13(2). DOI:10.7196/AJHPE.2021.v13i2.1268.

Krause, R., Barnard, A., Burger, H., De Vos, A., Evans, K., Farrant, L., Fouche, N., Kalula, S. et al. 2022. A Delphi study to guide the development of a clinical indicator tool for palliative care in South Africa. *Afr J Prim Health Care Fam Med.* 14(1):e1-e7. DOI:10.4102/phcfm.v14i1.3351.

LeBlanc, T.W. & Tulsky, J.A. 2011. Communication with the patient and family. . In *Oxford textbook of palliative medicine.* C.N. Hanks G, Christakis NA, Kaasa S, eds, Ed. Oxford: Oxford University Press,. 334-337.

Lerman, C., Daly, M., Walsh, W.P., Resch, N., Seay, J., Barsevick, A., Birenbaum, L., Heggan, T. et al. 1993. Communication between Patients with Breast Cancer and Health Care Providers. *Cancer.* 72(9):2612-2620.

Lewis, F.N. 1990. Strengthening Family Supports Cancer and the Family. *Cancer.* 65:752-759.

Lubuzo, B., Ginindza, T. & Hlongwana, K. 2019. Exploring barriers to lung cancer patient access, diagnosis, referral and treatment in Kwazulu-Natal, South Africa: the health providers' perspectives. *Translational Lung Cancer Research.* 8(4):380-391. DOI:10.21037/tlcr.2019.08.17.

Lutz, S., Norrell, R., Bertucio, C., Kachnic, L., Johnson, C., Arthur, D., Schwarz, M. & Palardy, G. 2001. Symptom Frequency and Severity in Patients with Metastatic or Locally Recurrent Lung Cancer: A Prospective Study Using the Lung Cancer Symptom Scale in a Community Hospital. *Journal of palliative medicine.* 4(2):157-165. DOI:10.1089/109662101750290191.

Maetens, A., Beernaert, K., De Schreye, R., Faes, K., Annemans, L., Pardon, K., Deliens, L. & Cohen, J. 2019. Impact of palliative home care support on the quality and costs of care at the end of life: a population-level matched cohort study. *BMJ.* 9(1):1-9.

Maione, P., Perrone, F., Gallo, C., Manzione, L., Piantedosi, F., Barbera, S., Cigolari, S., Rosetti, F. et al. 2005. Pretreatment Quality of Life and Functional Status Assessment Significantly Predict Survival of Elderly Patients With Advanced Non-Small-Cell Lung Cancer Receiving Chemotherapy: A Prognostic Analysis of the Multicenter Italian Lung Cancer in the Elderly Study. *J Clin Oncol.* 23(28):6865-6872.

Marks, S. & Anderson, N. 1987. Issues in the Political Economy of Health in Southern Africa. *Journal of Southern African Studies.* 13(2):177-186.

Marshall, B., Peter Cardon, P., Poddar, A. & Fontenot, R. 2013. Does Sample Size Matter in Qualitative Research?: A Review of Qualitative Interviews in is Research. *Journal of Computer Information Systems.* 54(1):11-22.

McIlfatrick, S. 2007. Assessing palliative care needs: views of patients, informal carers and healthcare professionals. *Journal of Advanced Nursing.* 57(1):77-86.

Mead, N., Bower, P. & Hann, M. 2002. The impact of general practitioners' patient-centredness on patients' post-consultation satisfaction and enablement. *Social Science & Medicine.* 55:283-299.

Michael, N., Beale, G., O'Callaghan, C., Melia, A., DeSilva, W., Costa, D., Kissane, D., Shapiro, J. et al. 2019. Timing of palliative care referral and aggressive cancer care toward the end-of-life in pancreatic cancer: a retrospective, single-center observational study. *BMC Palliat Care.* 18(1):13. DOI:10.1186/s12904-019-0399-4.

Miyashita, M., Hirai, K., Morita, T., Sanjo, M. & Uchitomi, Y. 2008. Barriers to referral to inpatient palliative care units in Japan: a qualitative survey with content analysis. *Support Care Cancer.* 16(3):217-222. DOI:10.1007/s00520-007-0215-1.

Morita, T., Akechi, T., Ikenaga, M., Kizawa, Y., Kohara, H., Mukaiyama, T., Nakaho, T., Nakashima, N. et al. 2005. Late Referrals to Specialized Palliative Care Service in Japan. *J Clin Oncol.* 23(12):2637-2644.

Movsas, B., Jennifer Moughan, J., Sarna, L., Langer, C., Werner-Wasik, M., Nicolaou, N., Komaki, R., Machtay, M. et al. 2009. Quality of Life Supersedes the Classic Prognosticators for Long-Term Survival in Locally Advanced Non-Small-Cell Lung Cancer: An Analysis of RTOG 9801. *J Clin Oncol.* 27(34):5816-5822.

Murray, S.A., Grant, E., Grant, A. & Kendall, M. 2003. Dying from cancer in developed and developing countries: lessons from two qualitative interview studies of patients and their carers. *BMJ.* 326:1-5.

National Department of Health, S.A. 2017. *National Policy Framework and Strategy on Palliative Care 2017-2022, Pretoria: NDoH, 2017*.

O'Boyle, C.A. 1994. The schedule for the evaluation of individual quality of life (SEIQoL). . *International Journal of Mental Health.* 23(3):3-23.

Oken, M.M., Creech, R.H., Tormey, D.C., Horton, J., Davis, T.E., McFadden, E.T. & Carbone, P.P. 1982. Toxicity And Response Criteria Of The Eastern Cooperative Oncology Group. *Am J Clin Oncol.* 5:649-655.

Olson, D.H. 2000. Circumplex Model of marital and family systems. *J Fam Therapy.* 22:144-167.

Palprac. 2018. https://palprac.org/about us, accessed 20 August 2023.

Parvan, A. 2015. Patients' substantialization of disease, the hybrid symptom and metaphysical care. *Journal of Evaluation in Clinical Practice.* 21:380-388.

Peters, S., Adjei, A.A., Gridelli, C., Reck, M., Kerr, E. & Felip, E. 2012. Metastatic non-small-celllung cancer (NSCLC): ESMO clinical practice guidelines for diagnosis, treatment, and follow-up. *Ann Oncol.* 23:vii56-64.

Rabow, M.W., Smith, A.K., Braun, J.L. & Weissman, D.E. 2010. Outpatient Palliative Care Practices. *Arch Intern Med.* 170(7):654-655.

Radbruch, L., de Lima, L., Lohmann, D., Gwyther, E. & Payne, S. 2013. The Prague Charter: urging governments to relieve suffering and ensure the right to palliative care. *Palliat Med.* 27(2):101-102. DOI:10.1177/0269216312473058.

Reid, E.A., Kovalerchik, O., Jubanyik, K., Brown, S., Hersey, D. & Grant, L. 2019. Is palliative carecost-effective in low-income and middle-income countries? A mixed-methods systematic review. *BMJ supportive & palliative care.* 9(2):120-129.

Roth, J.A., Goulart, B.H.L., Ravelo, A., Kolkey, H. & Ramsey, S.D. 2017. Survival Gains from First-Line Systemic Therapy in Metastatic Non-Small Cell Lung Cancer in the U.S., 1990–2015: Progress and Opportunities. *The oncologist (Dayton, Ohio).* 22(3):304-310. DOI:10.1634/theoncologist.2016-0253.

Sales, E., Schulz, R. & Biegel, D. 1992. Predictors of Strain in Families of Cancer Patients: A Review of the Literature. *Journal of Psychosocial Oncology.* 10(2):1-26.

Salins, N., Ghoshal, A., Hughes, S. & Preston, N. 2020. How views of oncologists and haematologists impacts palliative care referral: a systematic review. *BMC Palliat Care.* 19(1):175. DOI:10.1186/s12904-020-00671-5.

Sarradon-Eck, A., Besle, S., Troian, J., Capodano, G. & Mancini, J. 2019. Understanding the Barriers to Introducing Early Palliative Care for Patients with Advanced Cancer: A Qualitative Study. *J Palliat Med.* 22(5):508-516. DOI:10.1089/jpm.2018.0338.

Saunders, C. 2000. The evolution of palliative care. *Patient education and counseling.* 41:7-13.

Schenker, Y., Crowley-Matoka, M., Dohan, D., Rabow, M.W., Smith, C.B., White, D.B., Chu, E., Tiver, G.A. et al. 2014. Oncologist Factors That Influence Referrals to Subspeciality Palliative Care Clinics. *Journal of Oncology Practice.* 10(2):e37-e44.

Selman, L., Higginson, I.J., Agupio, G., Dinat, N., Downing, J., Gwyther, L., Mashao, T., Mmoledi, K. et al. 2009. Meeting information needs of patients with incurable progressive disease and their families in South Africa and Uganda: multicentre qualitative study. *BMJ.* 338:b1326.

Selman, L.E., Higginson, I.J., Agupio, G., Dinat, N., Downing, J., Gwyther, L., Mashao, T., Mmoledi, K. et al. 2011. Quality of life among patients receiving palliative care in South Africa and Uganda: a multi-centred study. *Health and Quality of Life Outcomes 2011, 9:21.* 9(21):1-14.

Sheridan, P.E., LeBrett, W.G., Triplett, D.P., Roeland, E.J., Bruggeman, A.R., Yeung, H.N. & Murphy, J.D. 2021. Cost Savings Associated With Palliative Care Among Older AdultsWith Advanced Cancer. *American Journal of Hospice & Palliative Medicine.* 38(10):1250-1257.

Simpson, M., Buckman, R., Stewart, M., Maguire, P., Lipkin, M., Novack, D. & Till, J. 1991. Doctor-patient communication: the Toronto consensus statement. *BMJ.* 303:1385-1387.

Smith, C.B., Nelson, J.E., Berman, A.R., Powell, C.A., Fleischman, J., Salazar-Schicchi, J. & Wisnivesky, J.P. 2012. Lung cancer physicians' referral practices for palliative care consultation. *Annals of oncology : official journal of the European Society for Medical Oncology /.* 23(2):382-387. DOI:10.1093/annonc/mdr345.

Smith, T.J., Temin, S., Alesi, E.R., Abernethy, A.P., Balboni, T.A., Basch, E.M., Ferrell, B.R., Loscalzo, M. et al. 2012. American Society of Clinical Oncology Provisional Clinical Opinion: The Integration of Palliative Care Into Standard Oncology Care. *J Clin Oncol.* 30(880-887).

Soni, A. 2001. *Top Five Most Costly Conditions among Adults Age 18 and Older, 2012: Estimates for the U.S. Civilian Noninstitutionalized Population.* Agency for Healthcare Research and Quality (US), Rockville (MD).

South African Palliative Care Conference. 2023. *https://hpca.co.za/2023-south-african-palliative-care-conference/.*

Sung, H., Ferlay, J., Siegel, R.L., Laversanne, M., Soerjomataram, I., Jemal, A. & Bray, F. 2021. Global Cancer Statistics 2020: GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries. *CA Cancer J Clin.* 71:209-249.

Temel, J.S., Shaw, A.T. & Greer, J.A. 2016. Challenge of prognostic uncertainty in the modern era of cancer therapeutics. *J Clin Oncol.* 34(30):3605=3608.

Temel, J.S., Greer, J.A., Admane, S., Gallagher, E.R., Jackson, V.A., Lynch, T.J., Lennes, I.T., Dahlin, C.M. et al. 2011. Longitudinal perception of prognosis and goals of therapy in patients with metastatic non-small-cell lung cancer: Results of a randomized study of early palliative care. *Journal of clinical oncology.* 29(17):2319-2326.

Temel, J.S., Greer, J.A., Muzikansky, M.A., Gallagher, E.R., Admane, S., Jackson, V.A., Dahlin, C.M., Blinderman, C.D. et al. 2010. Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer. *N Engl J Med.* 363(8):733-742.

Terre Blanche, M. & Durrheim, K. 2014. First steps in qualitative data analysis. In *Research in practice: Applied methods for the social sciences.* D.K. Terre Blanche M, Painer D, Ed.: University of Cape Town Press (Pty) Ltd.

Torre, L.A., Bray, F., Siegel, R.L., Ferlay, J., Lortet-Tieulent, J. & Jemal, A. 2015. Global Cancer Statistics, 2012. *CA Cancer J Clin.* 65:87-108.

Tubin, S., Khan, M.K., Gupta, S. & Jeremic, B. 2021. Biology of NSCLC: Interplay between cancer cells, radiation and tumor immune microenvironment. *Cancers.* 13(4):1-19. DOI:10.3390/cancers13040775.

Vasileiou, K., Barnett, J., Thorpe, S. & Young, T. 2018. Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. *BMC Medical Research Methodology.* 18:148.

Vinant, P., Joffin, I., Serresse, L., Grabar, S., Jaulmes, H., Daoud, M., Abitbol, G., Fouassier, P. et al. 2017. Integration and activity of hospital-based palliative care consultation teams: the INSIGHT multicentric cohort study. *BMC palliative care.* 16(1):36-36. DOI:10.1186/s12904-017-0209-9.

Von Roenn, J.H., Voltz, R. & Serrie, A. 2013. Barriers and approaches to the successful integration of palliative care and oncology practice. *Journal of the National Comprehensive Cancer Network.* 11:S11-S16.

Ward, A.M., Agar, M. & Koczwara, B. 2009. Collaborating or co-existing: a survey of attitudes of medical oncologists towards specialist palliative care. *Palliat Med.* 23(8):698-707. DOI:10.1177/0269216309107004.

Wentlandt, K., Krzyzanowska, M.K., Swami, N., Rodin, G.M., Le, L.W. & Zimmermann, C. 2012. Referral Practices of Oncologists to Specialized Palliative Care. *J Clin Oncol.* 30(35).

Wentlandt, K., Krzyzanowska, M.K., Swami, N., Rodin, G.M., Le, L.W. & Zimmermann, C. 2012. Referral practices of oncologists to specialized palliative care. *J Clin Oncol.* 30(35):4380-4386. DOI:10.1200/JCO.2012.44.0248.

Whelan, T.J., Mohide, E.A., Willan, A.R., Arnold, A., Tew, M., Sellick, S., Gafni, A. & M, L.M. 1997. The supportive care needs of newly diagnosed cancer patients attending a regional cancer center. *Cancer.* 80(8):1518-1524.

Whitmer, K.M., Pruemer, J.M., Nahleh, Z.A. & Jazieh, A.R. 2006. Symptom Management Needs of Oncology Outpatients. *Journal of palliative medicine.* 9(3). DOI:https://doi.org/10.1089/jpm.2006.9.628.

WHOQOL Group. The World Health Organization Quality of Life Assessment (WHOQOL): Position Paper from The World Health Organization. 1995. Soc.Sci.Med. 41(10): 1403-1409

World Health Assembly. 2014. *Strengthening of Palliative Care As a Component of Comprehensive Care Throughout the Life Course, Geneva, 2014*.

World Health Organisation. 2002. *WHO Definition of Palliative Care. 2002. World Health Organization. http://www.who.int/cancer/palliative/definition/en*.

Wozniak, K. & Izycki, D. 2014. Cancer: a family at risk. *Prz Menopauzalny.* 13(4):253-261. DOI:10.5114/pm.2014.45002.

Yadav, S., Heller, I.W., Schaefer, N., Salloum, R.G., Kittelson, S.M., Wilkie, D.J. & Huo, J. 2020. The health care cost of palliative care for cancer patients: a systematic review. *Support Care Cancer.* 28(10):4561-4573. DOI:10.1007/s00520-020-05512-y.

Appendix 1

An Exploration of Factors that Influence Referral to Palliative care in Oncology

Interview Guide: Oncologist

Thank you for agreeing to take part in this study which is exploring factors that influence referral to palliative care in oncology.

Let us start off with a shortened definition of Palliative Care as an approach that improves the quality of life of patients and their families, when faced with life-threatening illness, through the prevention and relief of suffering by means of early identification and treatment of pain and other problems that may be physical, psychosocial and spiritual

1. Perhaps you could tell me how you see the relationship between Palliative Care and Oncology?

2. Please share something of your experience with referring patients to palliative care

3. Could you please elaborate on the factors or reasons that influence your decision whether or not to refer your patients for palliative care?

   Increase in unplanned hospital admissions?

   Deteriorating Performance status, with limited reversibility?

   Significant weight loss over a few months?

   Too frail for cancer treatment or if treatment was for symptom control

4. What would be your response if a patient or family requested a referral to palliative care?
5. What would be your response if a patient or family chose to stop disease directed treatment?

6. Could you please tell me about patients that have been in your care where palliative care services were not involved, that you now, in retrospect, think could have benefitted from palliative care referral

7. Were there particular circumstances regarding these patients who were not referred, that prevented you from referring them?
   ? Disease: aiming for cure; symptom severity/complexity

? Patient: hoping for cure
? Family:

? Palliative care services: service provider scarcity/unknown

? Oncologist circumstances

8. Let us now talk about referring patients:
   When do you think it is appropriate for cancer patients to be referred to palliative care services/providers?
   What indicators should trigger referral to palliative care services?

9. What do you think of the notion that ALL patients with metastatic cancer should be referred to palliative care services?
   How, do you think, the patient and family might benefit

   How, do you think, the patient and family might be disadvantaged?

10. What do you think would facilitate referral from your practice to palliative care services?

Appendix 2

An Exploration of Factors that Influence Referral to palliative care in Oncology

Interview Guide: Patient

Thank you for agreeing to take part in this study which is exploring factors that influence referral to palliative care.

Let us start off with a shortened definition of Palliative Care as an approach that improves the quality of life of patients and their families, when facing life-threatening illness, through relief of pain and other problems that may be physical, psychosocial or spiritual

1. Now please would you talk to me about your overall care since you were diagnosed with cancer?

2. Can we then talk about those areas of care you think could have been improved

3. Would you please describe your experience of palliative care services?

4. What circumstances should trigger cancer patient referral to palliative care services?

5. What do you think of the notion that ALL patients diagnosed with metastatic cancer should be referred to palliative care services?

6. How, do you think, the patient and family might benefit from such a referral?

7. How, do you think, the patient and family might be disadvantaged?

8. How do you think your care might have been different for you or your family, had you been referred earlier or later to palliative care services?

? What about quality of life

? What about symptom control

? What about team collaborative effort, what outcomes might it give?

Appendix 3

Information Sheet for Oncologist:
An Exploration of Factors that Influence Referrals to Palliative Care in Oncology

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

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

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

What is the purpose of the study?

We are looking at factors that influence referrals to palliative care services in patients diagnosed with cancer.

Do I have to take part?

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

What will happen if I take part?

An experienced researcher will speak to you and ask you questions about you and your views on palliative care, in regard to your patients. It will take around 20-30 minutes for the interview. We would like to hear about your story. The interview will be recorded, and the recording and transcript will be kept confidential. This information sheet is for you to keep.

Benefits of the study

There are no direct benefits to the study for participants although people who have been interviewed using these questionnaires find that there are good points for discussion with fellow care

providers. The anticipated benefits are in identifying people's care needs and in trying to meet those needs.

What are the risks of the study?

There are no risks. Answering some questions might cause an emotional response. Your responses will not be divulged to your patients or anyone, other than the co-investigators. The researcher will stop the study should you reach a point where you wish not to continue with the interview.

Will my taking part in this study be kept confidential?

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

That information will be treated as confidentially as all the other information you give us, and no-one outside this study will be able to find out your name or any other information that would identify you.

How will I know about the results of the study?

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

Who is organising the research?

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

Dr Nosisa Matsiliza, telephone 083-2555682

If you have any questions about the study:

Dr Graham Bresick, University of Cape Town: Tel 021-4066510

If you have any questions about your human rights and 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: 021 406 6338

Appendix 4

Information Sheet for Patient:
An Exploration of Factors that Influence Referrals to Palliative Care in Oncology

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

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

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

What is the purpose of the study?

We are looking at factors that influence referrals to palliative care services in patients diagnosed with cancer.

Do I have to take part?

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

What will happen if I take part?

An experienced researcher will speak to you and ask you questions about you and your health, and this may include any pain or other problems you have. It will take around 30-60 minutes for the interview. We would like to hear about your story. This information sheet is for you to keep.

Benefits of the study

There are no direct benefits for participants although people who have been interviewed using these questionnaires find that there are good points for discussion with care providers. The anticipated benefits are in identifying people's care needs and in trying to meet those needs.

What are the risks of the study?

There are few study risks. Answering some questions might cause an emotional response. The researchers and counselors are trained to assist if the questions cause an emotional response. The researcher will stop the study and ask you if you would like assistance

Will my taking part in this study be kept confidential?

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

For patients in this study we will record their illness. That information will be treated as confidentially as all the other information you give us, and no-one outside this study will be able to find out your name or any other information that would identify you.

How will I know about the results of the study?

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

Who is organising the research?

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

Dr Nosisa Matsiliza, telephone 083-2555682

If you have any questions about the study:

Dr Graham Bresick, University of Cape Town: Tel 021-4066150

If you have any questions about your human rights and 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: 021 406 6338

Appendix 5

Consent form for Oncologist: An Exploration of Factors that Influence Referrals to Palliative Care in Oncology

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

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

3. I agree to take part in the above study.

Name _____

Signature _____ Date _____

Researcher: Signature _____ Date: _____

Witness: Name_____

(from clinical team or family member)

Signature _____ Date: _____

Appendix 6

Consent form for Patient: An Exploration of Factors that Influence Referrals to Palliative Care in Oncology

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

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

3. I agree to take part in the above study.

Name _____

Signature _____ Date _____

Researcher: Signature _____ Date: _____

Witness: Name

(from clinical team or family member)

Signature _____ Date: _____

Appendix 7

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	Matsiliza
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	MPhil
Occupation	3	What was their occupation at the time of the study?	Family Physicia
Gender	4	Was the researcher male or female?	N/A
Experience and training	5	What experience or training did the researcher have?	Master's level p
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	No
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	As per informa
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Motivation and
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Qualitative cro
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	purposive sam
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	telephonically
Sample size	12	How many participants were in the study?	Twenty
Non-participation	13	How many people refused to participate or dropped out? Reasons?	One did not re
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	Home & Workp
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	No
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	Patients with c
Data collection			

Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Yes questions
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	No
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	Audio recordir
Field notes	20	Were field notes made during and/or after the inter view or focus group?	Yes during inte
Duration	21	What was the duration of the inter views or focus group?	8-45 minutes
Data saturation	22	Was data saturation discussed?	Yes
Transcripts returned	23	Were transcripts returned to participants for comment and/or	Yes to oncolog
Topic	**Item No.**	**Guide Questions/Description**	**Reported on Page No.**
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	Two
Description of the coding tree	25	Did authors provide a description of the coding tree?	N/A
Derivation of themes	26	Were themes identified in advance or derived from the data?	Derived from d
Software	27	What software, if applicable, was used to manage the data?	N/A
Participant checking	28	Did participants provide feedback on the findings?	No
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Yes with partic
Data and findings consistent	30	Was there consistency between the data presented and the findings?	Yes
Clarity of major themes	31	Were major themes clearly presented in the findings?	Yes
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	No

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.