



Research dissertation

An evaluation of the current practices followed by oncologists in private practice in Cape Town, South Africa, in the management of patients with advanced cancer which no longer responds to anticancer treatment and the identification of the needs associated with such management

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Abbreviations

ESMO - European Society of Medical Oncology

FACT-L - Functional Assessment of Cancer Therapy-Lung scale

GP - General Practitioner

GVI - GVI Oncology

NSCLC - Non-Small Cell Lung Cancer

Abstract

Study rationale: Managing patients whose disease has become unresponsive to anticancer treatment confronts oncologists with major stressors which may range from the management of distressing physical symptoms to complex psychosocial issues. These sets of circumstances prompted the undertaking of this study: An evaluation of the current practices followed by oncologists in private practice in Cape Town, South Africa, in the management of patients with advanced cancer which no longer responds to anticancer treatment and the identification of the needs associated with such management.

Method: A descriptive qualitative study was selected for data collection. Cross-sectional, in-depth semi structured face to face interviews were conducted with fifteen radio-oncologists working in five satellite units of a private oncology company in Cape Town. The interviews were conducted with the aid of a topic guide. The process of coding was employed to organise and manage the collected data.

Results: The following six themes which had a bearing on the main topic were distilled from the data: Oncologists' experiences pertaining to the management of patients with advanced disease; the difficult discussion necessary when a patient's disease became incurable and when it had to be decided whether anticancer treatment should be stopped; the decision to stop anticancer treatment; advance directives; oncologists' burnout and the palliative care team approach.

Discussion and conclusion: A description of challenging aspects associated with the management of terminally ill cancer patients is given. Identified needs include training of staff in palliative care; guidance for oncologists regarding the discussion of and the decision to stop anticancer treatment; implementation of advance directives; the development and employment of a multidisciplinary approach to provide palliative care; and support for oncologists facing burnout. Recommendations were made pertaining to appropriate training in the field of palliative care; the development of guidelines to aid oncologists in the discussion of and decision to stop anticancer treatment and the implementation of advance directives; the provision of palliative care through employment of a multidisciplinary approach led by a

palliative care physician; and external support which should be provided by the oncologists' company to prevent and treat burnout.

CHAPTER 1: BACKGROUND

1.1 Introduction

The management of patients with advanced cancer which does not respond to anticancer treatment is often a major challenge for oncologists. Patients may present with a variety of problems ranging from distressing physical symptoms to complex psychosocial and spiritual issues. The complex care they need due to their advanced disease puts a great deal of stress on their families and on healthcare resources.¹ Despite the availability of palliative care services and the benefit of the palliative care approach in complex problems associated with patients suffering from advanced disease, the utilisation of palliative care services by their treating physicians remains low.² As a result the patients involved are deprived of the benefits of palliative care, such as the efficient treatment of depression, fewer hospital admissions, improved quality of life and even a substantial survival advantage. This was evident in the findings of the study undertaken by Temel *et al.* They confirmed that patients with metastatic lung cancer who received palliative care in the early phases of their disease, showed improvement in quality of life, experienced less depressive symptoms, required less aggressive end of life care and had a longer median survival when compared with patients who received only standard oncology care.³

1.2 Importance of advanced cancer care

The incidence of cancer is globally on the rise. The World Health Organization estimated that by the year 2020 more than 15 million people worldwide will have cancer. Of those, 10 million will die each year which will represent a 60% increase in deaths.¹⁰¹ Although 50% of patients with cancer are not cured, early detection and advanced cancer treatments result in patients living longer despite their advanced disease. These patients can experience profound distressing symptoms and psychosocial issues associated with advanced disease. Additionally, in view of the general aging of the population, these patients are usually older and thus at risk of developing co-morbidities and chronic diseases which will make their health needs much more complex.⁴ However, by combining palliative care with oncology treatment in the management of patients with advanced cancer, the quality of life and mood of these patients

can be considerably enhanced. This was shown in the results of a randomised controlled trial conducted by Bakitas *et al.* The trial demonstrated that the quality of life and mood of patients with advanced cancer who received nurse led intervention focused on palliative care improved noticeably when compared with those of patients who received usual oncology treatment.⁵ Such relief of complicated symptoms and other distressing factors associated with advanced cancer, brought about by the early implementation of palliative care, strongly emphasises the value of such an approach.

1.3 Caring for patients with advanced cancer

Patients suffering from advanced cancer present with distressing physical symptoms as well as complex psychosocial and spiritual issues. Such issues, which need to be identified and appropriately managed by the treating oncologist, include the following:

1.3.1 Pain and associated physical symptoms

Pain caused by advanced cancer is often complex and chronic.⁶ It is present in all phases of cancer and the assessment and treatment thereof is of utmost importance.⁷ In addition it may cause psychological symptoms, decline in performance status, spiritual or existential distress and social disruption. All of these may affect the quality of life of the patients and families.⁸ Yet studies have shown that pain suffered by cancer patients is still not adequately treated.⁷

Although pain is commonly associated with advanced cancer, other physical symptoms can also contribute significantly to the discomfort suffered by cancer patients. Fatigue and anorexia are the two most common symptoms associated with emotional and physical distress with pain ranked third. Other common symptoms frequently coupled with pain are dyspnoea, dizziness, tenesmus, nausea, constipation, delirium and confusion which all affect quality of life negatively.⁹

The early identification and impeccable assessment and treatment of pain and other distressing symptoms should therefore be a priority in the management of patients whose disease is no longer responding to active treatment. This can usually be achieved through a direct organised approach. Good pain management requires that the patient receives a thorough pain assessment, clear and consistent instructions and regular follow up visits to assess the

effectiveness of the regime. Good communication between the oncologist and the patient is essential.¹⁰ All treatment options, questions and concerns regarding pain control and general measures and advice to reduce pain should be discussed with and explained to the patient and family. The management of nonpain symptoms in advanced cancer patients includes identification and treatment of possible underlying causes by means of proper historical, physical and laboratory assessment as well as alleviation of the symptoms. As in the case of pain management, frequent evaluation and good communication is vital for proper symptom control.⁹

1.3.2 Psychosocial issues

It is well recognised that the diagnosis and treatment of cancer impact severely on the lives of patients and their families. Studies have shown that cancer patients experience a great deal of psychosocial symptoms and distress. Not only does the disease and its treatment cause physical distress but it also triggers emotional issues, role limitation and lack of social activities.¹¹ It has also been indicated that 35% of cancer patients present with psychological symptoms of anxiety, depression and changes of mood.¹¹ The quality of life of cancer patients suffering of depression is markedly affected. Their cancer tends to progress more rapidly and their cancer related symptoms, especially pain, tend to be more severe.¹² Psychological responses to major losses, such as loss of independence and loss of physical health, are also more prominent in advanced cancer patients. These responses are often seen at the time of or shortly after the initial diagnosis has been made, at the time of the first disease recurrence and as death approaches.¹³

Psychosocial issues associated with patients with advanced cancer are currently managed through adjunctive programmes such as psychotherapy, support groups and psycho-education. These services are usually provided by social workers, chaplains and counselors and should be in conjunction with medical care.¹² Modern medical practice has also recognised the importance of applying a patient centered model of care. In the fields of both oncology and general medicine approaches such as these, where physicians are encouraged to communicate in a patient centered way, have resulted in improved patient outcomes and recovery.¹¹

1.3.3 Spiritual issues

Spirituality and religion becomes highly significant when a patient approaches the end of his life. It is well recognised that spirituality and religion can affect a patient's quality of life, quality of care and satisfaction.¹⁴ Spiritual pain can be defined as a conflict situation that occurs between a person's belief structure and his current reality. It is experienced when there is conflict and disharmony between a person's hopes, beliefs and values and his personal experience with life. It often has its origin in a traumatic life shattering incident which influences a person's current life perspectives and purposes. This may cause disparate states like distress, loss, frustration, sorrow, disbelief and discomfort which, in turn, may trigger a poignantly painful condition.¹⁵ Studies have shown that a high prevalence of spirituality, religiosity and spiritual pain is observed in patients with advanced cancer who are receiving palliative care. Importantly, such patients regarded these issues as markedly significant which either improved or worsened their physical and psychological symptoms. Spiritual pain was also found to be associated with a decreased spiritual quality of life. Evidence showed that the addressing and supporting of patients' spiritual issues could lead to improvement in quality of care, higher hospice utilisation and less aggressive terminal care. Therefore, it is important to perform regular spiritual assessments to identify spiritual needs that ought to be addressed appropriately.¹⁴

1.3.4 A multidisciplinary team approach

The optimal management of the distressing symptoms and psychosocial issues associated with patients with advanced cancer requires a multidisciplinary team approach. The palliative care team and the treating oncologist are integral components of such a multidisciplinary team. Physical symptoms, psychosocial stress and spiritual issues may present at any time in the course of the illness. Hence it is essential to implement palliative care as soon after the diagnosis as possible to ensure proper management of needs and quality of care.¹⁶ By following a multidisciplinary approach, the treating oncologist may benefit from the wisdom and support of fellow team members. A successful team may possess a combination of strengths and skills which will not be available should the oncologist be functioning alone.¹⁷ With the support of the palliative care team, the treating oncologist can now focus his attention more on treating

the disease while the palliative care team will concentrate on symptom management and psychosocial issues.

The palliative care team should be familiar with the role of the oncologist in the team and must be informed about the cancer which is treated as well as of the effectiveness and side effects of the treatment. They should also be aware of any symptoms shown by the patient that may benefit from anticancer treatment. Such a case should be referred to the oncologists for consideration. Although palliative care teams are more likely to be involved in caring for patients with advanced and incurable cancers, patients with early or curable cancer in the adjuvant setting may also benefit from their expertise.¹⁶

1.4 Attitudes of treating oncologists

A survey regarding the attitudes of oncologists toward palliative care for patients with advanced and incurable cancers was performed by the European Society of Medical Oncology. This survey recognized the importance of palliative and supportive care of patients with incurable cancers. It was also found, regrettably but not unexpectedly, that most oncologists did not receive adequate training in palliative care during their residency training. Consequently and inevitably this leads to suboptimal levels of participation by oncologists in palliative care programmes later in their careers.¹

Oncologists are trained to treat aggressively and to cure where possible. If regular curing of patients is not accomplished, this mind-set can cause a great deal of stress for and even burnout of the oncologist. Contributing to this perception of failure is the pressure of the patient's and family's unrealistic expectations which often are in stark contrast with the reality of what can be achieved with the treatment of an advanced disease.¹⁸ In addition, continued exposure to the demise of patients with whom the oncologist has developed a relationship, was involved with their emotional conflicts and was expected to absorb their and their families' emotions of grief and anger can inflict major stresses on the treating oncologist.¹³

1.5 The cost of cancer care

Major advances in the understanding of cancers and the treatment thereof have led to a reduction in the rate of cancer deaths. Unfortunately these advances have been associated

with substantial cost increases. These increases add considerably to the financial burden on patients and their families and to the demands on national health care resources. Studies have shown that even patients with health insurance are negatively affected by the increase in treatment costs. Of these patients 25% were compelled to deplete their financial reserves to pay for oncology treatments while 33% struggled to such an extent to pay their health bills that they are faced with financial ruin.¹⁹

Treating oncologists are in a position to directly or indirectly influence the costs of cancer care. Their choice of treatment options or drugs, usage of imaging and special investigations, types of supportive care and decisions on hospital admissions substantially affect cancer care costs. Amongst the suggestions made to mitigate the impacts of increased cancer care costs was to better integrate palliative care into standard oncology care. Randomised trials have shown that, when compared with standard oncology care alone, the effective combination of palliative care with standard oncology care not only leads to longer survival by patients and enhanced patient and family satisfaction but also to meaningful cost savings. Furthermore, by applying better integrated palliative care, a patient's fear of abandonment can be reduced and his quality of life and life expectancy can be improved.²⁰

1.6 The role of chemotherapy in advanced stage disease

Progress in cancer related therapy has brought about significant improvements in overall survival of cancer patients as well as in response to treatment and toxicities. However, these treatments are associated with distressing side effects. Although some of these side effects are reversible, they can still undermine the patient's psychological well being and have a negative effect on his quality of life.²¹ This notwithstanding, chemotherapy remains the foundation of treatment of patients with advanced cancer in developed countries. The main aim of treatment is to prolong survival and to palliate symptoms.²²

The prevalence of chemotherapy related side effects, which influence the patient's quality of life, sometimes makes continuation of treatment unacceptable especially if the aim of treatment was palliation of symptoms. Appropriate cessation of chemotherapy plays an integral part in ensuring quality of life. Many oncology units regard cessation of chemotherapy

as a bench mark in quality assurance and improvement in clinical practice. The accepted approach is that chemotherapy should be stopped in the final two weeks of life. Usually less than 10% of patients receive chemotherapy during this period.²²

When chemotherapy is applied when death is certain and imminent, the question needs to be asked whether one is prolonging life or prolonging the process of dying. In some cases serious side effects associated with chemotherapy, such as neutropaenic sepsis, bleeding due to thrombocytopenia or bowel perforation, could be fatal and can then be regarded as hastening death. Therefore, a decision needs to be made if continuing chemotherapy in this scenario is appropriate or aggressive.²³ The following has been identified as markers for aggressive chemotherapy: The overuse of chemotherapy near the time of death; high rates of emergency unit visits; ICU admissions and hospitalisations of terminal patients as a result of chemotherapy related side effects; and underuse of hospice facilities due to lack of or late referrals of terminal patients.²⁵

Many reasons are presented for continuation of potentially futile treatment. Studies have shown that the treating oncologist plays an important part in this situation. Overestimation of prognosis and lack of important information provided to the patient and his family by the treating oncologist can lead to inappropriate continuation of treatment and may create a sense of false hope for the patient.²² When it does not acknowledge the reality of an imminent death, such false hope can lead to inadequate end of life arrangements and added suffering by patients and their family members.²⁴ Another possible cause for continuation of potentially futile treatment could be the recommendation of another line of lucrative chemotherapy to avoid the difficult discussion of cessation of treatment and implementation of palliative care.²²

On the other hand the prolongation of chemotherapy at the end of life may be insisted on by the patient and/or his family. This may be caused by a personality trait to persevere and to keep on fighting in hope for a cure or for the improvement of the chances of survival. Although continuation of treatment will give the patient a feeling of control over his disease and a sense of hope, it may delay acceptance of his preterminal condition and deny him and his family to prepare for an imminent death and proper bereavement.²²

Therefore, with the emphasis on quality of life, the treating oncologist should discuss openly with patients and families the prognosis of their disease and the desirability of further treatment. In such a discussion the efficacy and benefits of further chemotherapy treatment and the possible adverse effects and symptoms that may be experienced must be addressed frankly and it needs to be clearly stated that the chemotherapy is not going to effect a cure. Patients need to be made fully aware of the aggressiveness of cancer treatments and of the impact it may have on their lives and the lives of their family members. New approaches within the field of oncology and especially palliative care, which focuses mainly on enhancement of quality of life, should continuously be integrated in the care of patients suffering from advanced cancer.²¹

1.7 The role of the oncologist treating patients with advanced cancer

Globally, cancer is a major public health problem. It is responsible for more than 25% of all adult deaths in the United States. According to the latest cancer statistics the overall cure rate for cancers are less than 60%.²⁶ It is therefore no surprise that many patients may perceive cancer as a chronic disease that ultimately causes their deaths. These patients regard issues pertaining to quality of life as essential, irrespective of the illness trajectory and duration of survival. Therefore, their care should provide for quality of life dimensions by combination of disease specific treatment and palliative care according to the patients' clinical circumstances and their own priorities and preferences. In these cases the role of the treating oncologist is that of primary cancer caregiver and coordinator of clinical services. This can be very demanding and may be associated with complicated challenges which require a fair amount of cognitive, interpersonal and clinical skills.²⁷

The clear division of cancer care into two parts starting with disease specific anticancer treatment followed by symptom control and palliative care in the advanced stage is no longer appropriate. The treating oncologist's responsibilities towards his patient should not only comprise the provision of anticancer treatment but also the management of psychosocial, spiritual and clinical issues during all phases of care until the final phase of life. To accomplish this, the oncologist should be adequately trained to provide not only state of the art anti-

neoplastic therapy but also to provide appropriate palliative care. Obtaining palliative care training and training in the utilisation of specialised palliative care teams is necessary to enable oncologists to manage terminally ill cancer patients more efficiently.²⁸ Familiarisation with the field of palliative care will extend the oncologist's therapeutic range and will diminish the stress associated with treating patients with incurable disease and, consequently, will improve patient outcomes and will provide new avenues for clinical research and reward.²⁷

1.8 Communication in advanced cancer treatment

Diagnosis of cancer is often associated with feelings of fear, anxiety and uncertainty experienced by patients while questions about issues regarding mortality are also triggered. Consequently, cancer patients are also subjected to a fair amount of stress. Such stress can affect their ability to interpret and integrate complicated medical facts and information which underpin the difficult life changing medical decisions that need to be taken. These experiences are more intense in patients with advanced cancer where the balance between hope and despair in the search of a possible cure can cause great tension.²⁹ The quality of the care for patients in this situation is dependent on effective oncologist-patient communication, especially in patients with intense suffering and emotional stress. Patients who are given the opportunity to disclose their fears and concerns tend to cope with their circumstances better.³⁰

Despite the above, doctors and nurses sometimes are inclined to censor the information they disclose to their patients. Disturbing facts are withheld as an effort to prevent harm. Such less than honest disclosures of information usually occur when the patient first reports suspicious symptoms; at the confirmation of a diagnosis; when assumed benefits of disease specific therapy are discussed; at disease relapse or progression or at the end of life. By protecting the patient from the truth, well meant as it may be, more harm than good is often done. Furthermore it can lead to inconsistent messages given by other members of the multi-disciplinary team. Although the provision of these ambiguous or misleading messages may render some short term benefits while things are still going well, the occurrence of negative consequences in the longer term usually results due to such an approach.³¹

A patient who suffers from a life limiting disease needs time and space to adjust to and to come to terms with his disease. Realistic hope can only be given and reasonable objectives can only be set with honest disclosure of information.³¹ In this context the treating oncologist should ascertain from the patient what he defines as hope and what he hopes for in his particular situation. In the case of incurable disease, the oncologist should gradually guide the patient to let go of unrealistic particular hope for cure and progressively adopt more generalised forms of realistic hope. More rational aims that could be strived for may include a remaining life without pain and suffering; the presence of loved ones at the patient's death bed; personal matters that are in order; the reaching of spiritual peace and assurance that family members and children will be well cared for after the patient's death.²⁴

It is well known that an open and sensitive discussion on end of life issues with patients generally leads to less aggressive end of life treatment and enhanced quality of life in the days preceding death.²⁴ Therefore, effective and honest communication between a patient with advanced cancer and his oncologist or healthcare worker must be a priority.

1.9 Patients' preferences for prognostic information about their disease

Surveys have indicated that most patients want extensive information on their prognosis. The kind of prognostic information required is usually influenced by the patients' cultural backgrounds, their views on hope and their acknowledgment or not that information on a poor prognosis can influence psychological processes.³² In some cases discrepancies can occur between the information given by the oncologists and their patients' understanding thereof. Medical information is often poorly absorbed and communication is often affected when patients are confronted by an incurable disease. Patients are prone to misinterpret the given information usually more positive than it was intended to be.³³ This can lead to unrealistic hope, for instance that a patient with a 10% chance to survive five years might regard himself to be in the 10% group.

It has further been reported that the manner in which prognostic information is given to patients can affect patients' satisfaction, depression, anxiety, hope and the patients' views on the possibility of applying alternative therapies. Most patients require information about life

expectancy, the extent of disease progression, how the cancer will affect their lives and on the possible side effects of disease specific treatment. It has also been shown, however, that most patients want their oncologists to request their permission before discussing such information and that the information is given in a direct and honest manner. Patients prefer that their oncologists use both positive and negative language to convey the news. They would rather prefer that a friend or relative is present and that the communication takes place in a private arrangement. Patients usually appreciate when the oncologist summarises the contents of his communication, checks understanding thereof and listens to and addresses their fears and concerns.³⁴ Maintaining or sustaining hope is a very important factor for the patient when prognostic information is disclosed. Patients seem to be more flexible in their formulation of hope and do not necessarily interpret it in terms of a biological cure, as their treating oncologists do. They derive it from the interaction with their oncologist, even if the information is unfavourable.³²

1.10 The oncologist's role in communication

It has been reported that most oncologists find it difficult to discuss prognostic information with their patients, especially when their disease becomes incurable.³² They are aware of their responsibility to discuss their patients' prognoses and the role it will play in the planning of advanced care and the setting of goals. There is evidence that oncologists, when communicating information regarding poor prognoses to their patients, experience unpleasant and troublesome emotions of unhappiness and frustration and even exhaustion. This can lead to variable physician behaviour in disclosing prognostic information.³⁴

It is important that oncologists must have frequent and objective discussions on treatment options with their patients throughout the course of their disease. Comprehensive information should be given about their disease status and treatment options. During these discussions the amount of detail should be tailored to the individual patient and due consideration should be given to the patient's wishes. When discussing disease specific anticancer treatment, it is important to mention the aim of treatment (whether curative or palliative), the likelihood of response and possible side effects and toxicities which may occur. By presenting pessimistic

information together with optimistic information instead of following only an optimistic approach can lead to better understanding and informed consent. The financial impact of disease specific treatment should also be discussed.³⁵

Communication hurdles may be encountered when the decision to stop anticancer treatment is to be or has been made. Patients often do not grasp what their oncologists tell them. Their physical weakness and the mental stress associated with their advanced disease can impede their ability to understand what they have been told. This often causes irrational decision making. The stress associated with the bad news can also cause the patient to transfer the responsibility to take the decision to an immediate family member or even to the oncologist. This may lead to treatment that is different to what the patient wants. Oncologists may also find it difficult to recommend that curative treatment be stopped as it may be perceived as an admission of failure. It would be much easier and more acceptable to the patient and his family if another round of chemotherapy is suggested, even though it is a mere catching at straws.³⁶

Given all the complexities associated with cancer care, the vast variety of anticancer treatments and the high expectations of the patient and his family, it is obvious that communication with the patient and his family is a significant part of the oncologist's role in caring for patients with advanced cancer and an important topic for training.²⁷

1.11 Advanced care planning

When a patient's cancer has progressed and is no longer responsive to anticancer treatment, decisions have to be taken regarding the aim of further medical treatment. This aim could be to prolong survival, alleviate distressing symptoms or to improve quality of life. The patient's preferences regarding the aim of treatment and the balance between benefits and side effects of treatment are very important factors that need to be taken into account when taking these decisions. It is important to discuss treatment preferences and possible directives for advanced care already in the early phases of a patient's disease. This approach will ensure the involvement of the patient in medical decisions that will influence the final phases of his life.³⁷

Advanced care planning is a process which, although voluntary, is advisable to be undertaken with patients who appreciate their current conditions and its potential future effects. The

discussion of advanced care planning must include the patient's preferences, feelings or belief about personal goals or aspirations for care, his disease and prognosis, different types of treatment that are available and their benefits, harms and risks and possible decisions that need to be taken about his future care and treatment.³⁸

An important outcome of the discussion will be the identification of options for future care and treatment, or the refusal thereof in specific circumstances. The options decided upon should be recorded and be communicated to those who will be responsible for the patient's care or treatment, be it family or care givers. This step is necessary as progression of the disease may result in the patient losing his capacity to take rational decisions due to the possible occurrence of delirium and cognitive impairment. Alternatively, the patient may decide or be encouraged to nominate someone known as a "proxy decision maker" to be consulted and to take decisions on his behalf when he is unable to do so.³⁸

Guidance and participation by the physician, family participation and the use of structured material to foster discussion and documentation are essential factors which will ensure the success of the process.³⁹ Discussions on advanced care may also bring about an increased sense of control with the patient which will help him to anticipate the decisions that will have to be taken as his illness progresses. This will also reduce anxiety in proxy decision makers which, in turn, will improve the teamwork of the professionals.³⁸

The issues mentioned above again emphasise the importance of addressing advanced care already during the early phases of the disease. This action may in some cases be very difficult as it may confront the patient with the reality of imminent death for which he may not yet be ready. It may also affect the patient's particular hope for a cure for his disease. It is therefore important that the oncologist only enter into discussions regarding advance care planning when the patient and family are ready to listen, hear and talk about this topic. Patients with little or no interest should be questioned about it once a year or sooner when their condition deteriorates. Patients who are showing some interest should be given written information, websites or educational materials with a view to discussing these issues at future appointments.⁴⁰ The failure to plan for advanced care or to prepare clear directives may result

in unnecessary aggressive cancer care once the patient has lost capacity to take decisions thereon. This can lead to inadequate care and resultant poor quality of life for the patient as well as complicated bereavement for family members and care givers.⁴¹

An important matter which should be addressed in advanced care planning and directives is the issue of active resuscitation. It is generally accepted that active resuscitation is inappropriate for patients suffering from advanced metastatic disease. Patients who experience an in-hospital arrest have a 13% to 15% response rate to a resuscitation attempt and will eventually die in hospital.⁴³ Patients who are told that their chances of surviving six months are more than 10% often want life prolonging care. On the other hand, if the chances of surviving six months are less than 10%, patients often opt to decline active resuscitation and choose palliative care only.⁴² By disclosing an accurate prognosis and illness trajectory the treating oncologist will help patients suffering from advanced stage disease to make sensible choices with regards to active resuscitation. This will also put both care givers and family members of patients who might not be aware that the disease has become incurable on an equal footing regarding the current disease status and treatment aims.⁴³

Ideally, advanced care planning is a frequently reviewed and updated process of structured discussion and documentation which is woven into the regular healthcare process. Its aim is to ensure that the wishes of the patient are respected in decisions regarding his further treatment and care when he is no longer able to participate in such decisions.³⁹

1.12 The multidisciplinary team approach

The challenging needs of patients whose diseases are not responding to curative treatment require a range of expertise to ensure that the patients' end-of-life care fulfills all the wishes and desires of the patients and those close to them. Palliative care plays an important role in addressing these needs. It embraces different frameworks and approaches to adequately provide in every need of the patient. Thus, team work has become an essential part of palliative care through the years, drawing heavily on wide-ranging disciplines, knowledge, experience, skill and creative thought. Palliative care teams may consist of nurses, doctors, social workers, psychologists, chaplains, healthcare volunteers and a multitude of other treatment modalities.

Oncologists who engage in teamwork benefit from the support and wisdom of such a diverse team which provides a valuable basis for collaborative care.⁴⁴

1.13 Advantages of teamwork

Numerous studies have shown that the provision of healthcare through a team effort is much more effective than the provision thereof through a single practitioner. By following the team approach both quality and quantity of services are improved. Teamwork enhances communication and coordination which leads to a more efficient utilisation of the available professional expertise. These factors are conducive to beneficial outcomes such as reduced hospital admissions, less time spent in hospital, decrease in costs and improved accessibility for patients. More can be achieved through a team effort than can be realised through the sum of the capabilities of the team members operating individually.⁴⁵

It has been shown that the diversity of clinical expertise in a multidisciplinary team was responsible for clinical decisions which caused considerable improvement in patient care and organisational effectiveness. As such it is a source of work stimulation and reward and leads to a work environment wherein team members support each other and give valuable feedback. By working together problems and stressors as well as successes are shared. This may lead to more effective resolution of conflicts which, in turn, further contributes to improving quality of care.⁴⁵

1.14 Burnout of oncologists

1.14.1 Oncology: A complex and demanding profession

Oncology as an occupation comprises diagnosis of complex medical conditions, administration of advanced individualised anticancer treatment regimes and the provision of critical support to patients suffering from challenging life limiting diseases. However complex, caring for patients with cancer can be very rewarding to the treating oncologists. The combination of the advances in science which have led to improved prognoses for patients, the progress in the field of palliation and the opportunities to connect with patients and to show compassion can enhance meaning and purpose in the profession of the oncologist.⁴⁶

Yet, despite these real occupational benefits, caring for patients with cancer is a very demanding and stressful task. Oncologists are faced almost on a daily basis with complicated decisions. These decisions relate to life and death issues such as the provision of cytotoxic anticancer treatment with a narrow therapeutic window which has a limited ability to improve the survival prospects of many patients. Such constant dealing with suffering and death can cause depression, cynicism and a sense of futility. In addition, the oncologist must keep up to date with rapidly advancing treatment regimes and keep abreast with a steadily increasing volume of information. Moreover, oncologists have to deal with escalating productivity requirements, reduced autonomy and the ever expanding administrative responsibilities required of all physicians. This growing burden on the oncologist leads to burnout, a syndrome characterised by a lack of enthusiasm for work, depersonalisation and a loss of meaning in work. According to studies this syndrome affects 25% to 35% of medical oncologists, 38% of radiation oncologists and 28% to 36% of surgical oncologists.⁴⁶

1.14.2 Causes of burnout

Although burnout is well documented in physicians of all specialties, oncologists are at particular high risk due to their constant exposure to the death and suffering of their patients. In addition, many other factors can cause emotional exhaustion and burnout in oncologists. Recent studies have shown that, excluding deaths and suffering of patients, the major causes of burnout amongst oncologists are heavy patient load, keeping current with the latest literature, delivering bad news to patients and finding a balance between work and personal life.⁴⁷ In the past oncologists used to own their practices, hired their own staff and firmly controlled their patient load, working hours and work pace. Nowadays they are employed by private companies, hospital groups, cancer centers or academic institutions and have much less control over these working conditions. Productivity targets are set by business management and remuneration is calculated in accordance with the number of patients seen. Expensive anticancer treatments need to be authorised by medical aid schemes. Compilation of motivations for such authorisations adds to the daily burden of administrative work and, in turn causes extra stress.⁴⁶ In addition, difficulties in finding a balance between the oncologist's personal and professional life is another common cause of distress. Studies have shown that

inadequate time away from work is regarded as the single major cause of burnout in oncologists.⁴⁷

In contrast with the comments by palliative care clinicians regarding the personal and professional satisfaction they experience when they succeed in relieving the suffering experienced by their patients, they may ultimately realise that, due to burnout, they are not so caring and motivated as they once were. They may also become conscious thereof that they no longer enjoy their work, that they have lost that special connection they once had with their patients and that they have given up on personal activities that used to rejuvenate them. Such a realisation can precipitate an existential searching and loss of professional direction.⁴⁷

1.14.3 Alleviating burnout

Due to the fact that most oncologists will experience some degree of burnout during their career, it is important to emphasise that recovery from burnout is possible. It often requires an honest appraisal of personal and professional factors that may be responsible for burnout and a concerted effort to find ways to address these factors and to effect the necessary changes.⁴⁶ Several practical suggestions can be followed by the oncologist to prevent burnout. Good, uninterrupted sleep is important to deal with stressors and to promote clear thought. Sharing night and weekend calls with colleagues should therefore be routine and necessary. Short periods of rest during the working day are also necessary to prevent fatigue and to improve productivity. Extra time should be allowed to connect with patients. Such interaction may not only be refreshing to the oncologist but may also reconnect him with some of the original reasons which determined his choice of profession. Physical activity and hobbies are good for promoting a sense of well being and laughter and humor is good for personal and staff morale.⁴⁸

The prevalence of burnout can also be reduced by forming clinical health teams where team members can clinically and emotionally support one another.⁴⁸ It is important that a supportive environment and working relationships are upheld within the clinical team. Regular team meetings are necessary to evaluate and reflect on complicated situations encountered by members of the team, to promote shared decision making about the care of the patients, to

respect each other's expertise and to provide meaningful support to each other. These meetings can also be used as an opportunity for the members to express work related feelings and to openly discuss problems of the workplace.⁴⁹ Each team member needs to develop a sense of self awareness which will alert him when his stress levels are rising and which will enable him to recognise what encourages and exhausts him in his work. Effective training and mentoring by experienced clinical care workers can aid immensely in developing professional competence within the team.⁵¹

Burnout is a common feature in oncologists which has profound personal and professional consequences. Given the serious consequences that can be associated therewith, oncologists owe it to themselves, their patients and their families to commit to measures to alleviate burnout and promote personal health.⁴⁶ Time management and positive adaptive strategies are essential for a successful and happy practice.⁴⁸

1.15 Conclusion

Despite rigorous efforts to prolong life in their field of practice, oncologists inevitably encounter patients whose disease does not respond to curative treatment. While important advances have been made in the treatment of cancer over the past decade, more or less half of all current cancer patients will eventually succumb as a result of their disease or associated complications. Therefore, caring for patients as they die is a prominent part of an oncologist's daily practice. This can generate arduous stressors and demanding challenges which may eventually affect the quality of care provided.⁵ It is for this reason that the researcher will evaluate in this study the current practices followed by private oncologists when managing patients whose disease does not respond to anticancer treatment. The purpose of this evaluation will be to identify needs and to develop recommendations to essentially optimise quality of care and to ensure support for the treating oncologist.

It has been described that, regardless of all the fixations and preoccupations of oncologists in their efforts to cure their patients, no experience will give greater satisfaction or provide firmer confirmation of the soundness of their choice of occupation than by bringing comfort and dignity to a terminal patient at the end of his life.⁵⁰ However, as a medical officer employed by

a private enterprise specialising in cancer care, the researcher has witnessed firsthand many challenges associated with cancer care in the private sector. The high expectations of private patients and their families together with the stress associated with the requirement to increase the throughput of patients to enhance the company's profitability are some of the frustrating factors to be dealt with on a daily basis. Although high standards of care are maintained it is the researcher's view that the main focus of cancer care in the private sector is primarily on evaluation, staging and the initiation of lucrative anticancer treatment while palliative and supportive care are not receiving the attention it deserves. One of the purposes of this study will be to determine the validity of this view.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

Patients diagnosed with advanced, incurable cancer present a major challenge to their treating oncologists. Oncologists may be faced with complex emotions associated with the impact of a life limiting disease and with difficult decisions to be taken on treatment which has a limited chance of being beneficial. In addition, the presence of distressing physical symptoms and the challenge of maintaining hope despite bleak prospects are equally taxing.⁵² Numerous studies have been conducted on patients suffering from advanced disease with regards to issues such as symptom management, quality of life, patient and family experiences, of an ethical nature and pertaining to communication. However, little qualitative work has been published, especially in South Africa, regarding the current practices and identified needs of oncologists treating such patients. Important aspects of the treating oncologist's management of patients suffering from incurable cancer have been researched from the literature. Search engines used for the literature review included PubMed, Google Scholar and EBSCO HOST and key words used included advanced cancer, incurable cancer, palliative care, palliative chemotherapy, end of life care, communication in oncology, qualitative study of oncologists, multidisciplinary approach, palliative care team, oncologist burnout, advance directives, advance care planning and palliative care in South Africa.

2.2 The oncologist's experience of managing patients with advanced disease

2.2.1 Attitudes towards palliative care

Despite all the latest advances in cancer treatment, the mortality of patients diagnosed with cancer remains high. Cherny and Catane, both reputable authors in the field of palliative care, reported on the European Society of Medical Oncology's (ESMO) survey on oncologists' involvement in and attitude towards palliative care.¹ The rationale and aim of the study were clearly stated. It was prompted by the fact that the care of patients with advanced disease represents a major part of the work load of oncologists in Europe and the world and is associated with stress and other complexities. Hence, the aim of the survey was to gather information which could be used to improve the quality of supportive and palliative care rendered by the oncologists. The survey tool used had been developed by a focus group of

oncologists who were members of the Palliative Care Working Group of the ESMO. It was validated also by oncologists of the Working Group in collaboration with the executive of the ESMO. The population was clearly identified as ESMO oncologists. A total of 738 responses (82.5%) were received from 35 European countries and from five other continents which adequately allows for generalisation of the results.

The results gathered from the survey were clearly and appropriately presented. Of the 895 members who responded to this survey 69% reported that their practices included patients with advanced disease. Of the latter respondents 74% indicated that they derived satisfaction from their involvement with end of life care. Most of the responding oncologists acknowledged the importance of the provision of palliative care to patients with advanced disease and during the dying process. However, many admitted that they had not been adequately trained for the task and, in view thereof, had not participated in palliative care. Only a minority of oncologists involved palliative care specialists, hospice services, home based palliative care and psychologists in the care of these patients. The majority of the oncologists were more comfortable with the management of physical symptoms such as pain, fatigue, nausea and vomiting than with the management of psychological symptoms such as depression and anxiety and with the provision of end of life care.

The survey confirmed that most oncologists who participated were positively inclined towards palliative and end of life care. However, it is a cause for concern that, despite this positive attitude, most oncologists did not receive adequate training in palliative care and were not equipped to deal with psychological aspects and end of life care. Skills in these areas are essential when managing patients with advanced diseases. The authors mentioned that possible bias might have been present in that the majority of respondents were clinicians with an interest in palliative and supportive care. The fact that oncologists with active interest in palliative care are not comfortable in dealing with non physical palliative care related problems due to lack of training, confirms that effective palliative care is seriously hampered by inadequate training.

2.2.2 The ability of oncologists to identify psychosocial distress in cancer patients

Sollner *et al* conducted a study to determine oncologists' ability to identify cancer patients who suffer from significant distress, who do not have proper social support and who are in need of psychosocial counseling. Their premise was that oncologists should play a vital role in the identification of cancer patients who are experiencing psychosocial distress and in the prevention of such distress. Their literature review, which was comprehensive and up to date, identified a considerable number of recent relevant studies aimed at the evaluation of the skills of oncologists to identify psychosocial problems experienced by their patients. They identified 298 cancer patients, who were receiving radiotherapy, by means of validating screening methods as experiencing psychosocial distress and being in need of support. These patients were assessed simultaneously by eight oncologists for psychological distress; assistance received from social networks and need for psychosocial support. The fact that the study was performed at a single radio-oncology unit does affect generalisation of results. The results showed that the oncologists were highly able to identify patients who experienced moderate distress. However, their ability to recognise patients experiencing severe distress was low. Of the 30 patients in the group who were experiencing severe distress the participating oncologists were able to identify only 11. These results, together with the fact that 20% to 40% of all cancer patients are emotionally distressed led the authors to conclude that a real need exists for the development of measures aimed at enhancing the ability of oncologists to identify psychosocial distress in their patients and to ensure their referral for proper support and counseling. These measures could include the development of screening instruments to detect distressed patients or the training of oncologists to be aware of psychosocial distress in patients.⁵³

Passik *et al* studied the ability of physicians to recognise depression in a large group of ambulatory cancer patients. Signs and symptoms of depression were often missed because oncology examinations focus mainly on physical issues and symptom management. Emotional and psychological symptoms were frequently perceived as normal consequences of a terminal illness and, therefore, were overlooked. Physicians participating in the study were asked to rate their patients' levels of depression symptoms, anxiety and pain. In turn, the patients were

requested to complete the Zung self-rating depression scale which had been described by several studies as a reliable and valid instrument. It was found that the participating oncologists often inaccurately assessed their patients' depression symptoms. Interestingly, patients with depression also reported higher levels of pain and disability. This shows that untreated depression may intensify many oncology outcomes which, in turn, may affect quality of life and even possible overall survival.⁵⁴

2.2.3 Integration of palliative care into standard oncology practice

Studies have suggested that palliative care should be integrated into standard oncology practice when a patient is diagnosed with advanced cancer or metastatic disease. Bakitas *et al* conducted a qualitative study on oncologists to determine their perspective on concurrent oncology palliative care and to understand their perspective on advanced cancer care. It was a well constructed study with a sample size of 35 oncologists. However, no information of the interviewers was given. It was only noted that they were trained by the authors. Also, nothing was mentioned about how the participants would be protected from harm, such as sensitive information which could elicit emotional responses. Ethical considerations were not mentioned.⁵⁵

According to the authors, this was the first study in which oncologists' experiences with advanced cancer patients in a concurrent oncology palliative care environment were described. It was found that the participating oncology clinicians treated patients with advanced cancer in a more holistic way and focused on quality of life rather than duration. This approach differed slightly when the treatment aim was curative in that patients were encouraged more to tolerate toxic side effects of chemotherapy. The clinicians valued the transition to palliative care but also emphasised the importance of timing and sensitivity. The introduction of early palliative care in concurrence with oncology treatment, the interdisciplinary approach and palliative care assistance with difficult discussions with patients and families were all viewed favourably by the majority of clinicians. This study showed that the participating oncologists strongly believed that concurrent palliative and oncology care should be the standard of care for patients with advanced disease.⁵⁵

Temel *et al* also hypothesised that early integration of palliative care with oncology treatment would enhance the quality of life of advanced cancer patients, decrease the occurrence of depression symptoms and would require less aggressive end of life care. The study design was clearly identified as a non-blinded randomised controlled trial where newly diagnosed non-small cell lung cancer (NSCLC) patients were assigned to receive either standard oncology care or standard oncology care integrated with palliative care. Quality of life and patient mood were assessed with valid and reliable scales namely the Functional Assessment of Cancer Therapy–Lung (FACT-L) scale and the Hospital Anxiety and Depression Scale. The results demonstrated that patients who received integrated palliative oncology treatment showed an improvement in overall survival of two months when compared with patients who received oncology care only. It was suggested that this could be due to earlier hospice referrals with better symptom management which could have led to disease stabilisation and prolonged survival. This particular care model also resulted in improved documentation of the patients’ resuscitation preferences and in less aggressive end of life care.³

The fact that the study was performed at a single tertiary institution and that only participants who were able to read and respond to questions in English had been recruited, limited the application of the results to other care centers or other ethnic groups. Temel *et al* also did not mention the cause of death of the patients, such as chemotherapy related deaths, infection or dehydration. Had the causes of deaths been known, the data then available could possibly have supported early integration of palliative care. In such an event it could have been inferred that the deaths of patients with advanced cancer who died at home possibly due to dehydration or infection could have been prevented if home based palliative care had been implemented. Nevertheless, the conclusion was clear and comprehensive: Patients with metastatic NSCLC who received early palliative care in their disease experienced significant improvements in both quality of life and mood as well as longer survival.

Muir *et al* evaluated the integration of an embedded palliative care clinic in a private outpatient oncology practice. This study is important because, consistent with trends, oncology practices have become progressively outpatient based with more than 90% of chemotherapies being

administered through this practice. This investigation was also considered a pilot study as, according to the author's knowledge, embedded palliative care clinics in a private outpatient oncology unit had not been described before. Patients attending these clinics also presented with a high volume of multiple symptoms and a potential prevalence of psychosocial distress. The objectives of the study were to assess quality care outcomes for patients, satisfaction provided, the volume of palliative care consultations and time saved for the oncologists. Symptom burden and relief were measured by application of the Edmonton Symptom Assessment System and by physician acceptance of palliative care services through a provider satisfaction survey. The volume of referrals and billing information were used to determine time saved for the oncologists. The embedded palliative care clinic was initiated at one half day per week and consisted of a certified palliative care physician and a palliative care fellow. It might have been more effective had the palliative care clinic involved more members of the palliative care team, such as a social worker, counselor or spiritual advisor to provide extra psychosocial and spiritual support. Nevertheless, the results were positive and showed that embedding a palliative care clinic in a private outpatient oncology unit is feasible. This service has the potential to improve symptom control and care for patients and also the effectiveness of the time spent by the treating oncologist.⁵⁶

The above mentioned studies demonstrated that early integration of palliative care with oncology treatment should be the standard of care. Some oncologists may regard the early referral of patients for palliative care as a failure to cure the patient. Traditional medical schools focus primarily on curative measures which can make the transition from curative to palliative care difficult to accept. This was identified in a study performed by Melvin *et al* as one of the barriers to early integration of palliative care.⁵⁷ Fortunately the importance of early integration was strongly confirmed by oncologists participating in the above mentioned studies and the results promised to alleviate distressing symptoms and improve quality of life of patients with advanced disease. Implementation of this practice in private oncology outpatient units with the aid of embedded palliative care clinics not only enhanced quality of care for the patient but also provided support for the treating oncologists.

2.3 Communication with patients presenting with advanced disease

Communication is a crucial part of caring for patients with advanced cancer. Such patients present with complicated physical symptoms and potential psychosocial issues. The emotional impact of their disease together with the effects of toxic chemotherapies which offer limited benefits and the challenge to balance hope with realistic goals affect the interpretation and integration of information by patients. Thus, communication often is a very challenging feature of an oncologist's profession.⁵² Oncologists regard the following situations which commonly occur during cancer care as particularly challenging from a communication perspective: Transition from curative treatment to palliative care; cessation of anticancer treatment; continuing with or withdrawing from life-prolonging medical treatment not knowing whether it is or is not life prolonging; discussions about death and dying; and dealing with the emotional responses of the patient and his family members. In these circumstances skillful, discrete and sympathetic communication which comprises listening, questioning, exploring and feedback are essential to build realistic hope. Experience and appropriate training can measurably increase the oncologist's competence in this particular field.⁵⁸

2.3.1 The oncologist's perspective

Cherny reported on a study undertaken by the ESMO on European oncologists' attitude towards information disclosure to patients with advanced cancer.⁵² Oncologists were requested to complete an online survey aimed at evaluating their attitudes and clinical behaviour relating to disclosure of information to such patients. The research tool that was used had been extensively peer reviewed to establish its validity before commencement of the study. Although 298 completed questionnaires were returned the response rate of 7.9% was quite low. The fact that the survey was conducted in English might be one explanation for the low response rate. The data collected during the survey showed variability in behaviour between physicians as well as variability in behaviour of a physician with regard to different patients. The data further added to preexisting knowledge that oncologists found it very difficult and were sometimes unable or unwilling to disclose information to patients regarding diagnosis, prognosis and the likely responses to treatment, even if such information was requested. The survey however did not provide information on the reasons why oncologists had found it so

difficult to disclose such information. These findings recommended the encouragement of the development of positive attitudes amongst oncologists towards the disclosure of relevant information to their patients.

Jackson *et al* conducted a qualitative study of oncologists' approaches to end of life care. Eighteen oncologists underwent a face to face survey and in-depth semi-structured interview during which they were asked to describe factors relating to the most recent in-patient death in their medical oncology service. The main aim of the study was to better understand how oncologists provide end of life psychosocial care and how this care affects job satisfaction and burnout. This understanding can be best achieved by using the exploratory methods associated with a qualitative study design, therefore justifying the authors' choice of this particular design. The authors also used quantitative methods in the form of close ended questions as part of the interview. The Maslach burnout inventory was used in combination with the semi-structured interview to assess emotional exhaustion, depersonalisation, and personal accomplishment of the treating physicians. This information will assist physicians in relating the story of their most recent patient death. By using a combination of both quantitative and qualitative study designs, the authors tried to get a deeper understanding of the physicians' experiences in the care of dying patients. Although the authors mentioned that a certificate of confidentiality was obtained to protect respondents from liability associated with their disclosures, no other ethical considerations were mentioned, such as the informed consent process or help in cases of possible burnout identified amongst participants. Furthermore, the fact that the study was only performed at two specialised referral institutions may limit generalisability of the findings to oncologists practicing in other units. Nevertheless the findings were clearly described and showed that oncologists who embraced both biomedical and psychosocial aspects of care were able to communicate more clearly about end of life care, felt more satisfied with the care they provided to terminally ill patients and their families, did not regard progression of the disease as due to personal failures and also felt less burnt out. They also understood that communication about end of life decisions with patients and their families is a process involving numerous discussions over time. Usually, a single conversation on these difficult decisions leaves minimal time for closure in dealing with the emotions associated therewith.⁵⁹

The timing of such discussions were also emphasised by Cherlin *et al* in their study relating to communication between physicians and family caregivers about end of life care. Three key subjects for patient-caregiver and -physician communication were identified and described during the study: Communication that the patient's disease is incurable; communication pertaining to life expectancy and communication regarding hospice referral. A comprehensive literature review was conducted which showed substantial limitations of the reviewed studies performed in the field of patient-caregiver and -physician communication. Previous studies focused mainly on hospice discussions but not on the timing of such discussions, on patient experiences with inadequate attention being paid to the experiences of family caregivers and on the investigation of family caregivers of patients who were not in their final phase of life. As in the case of Jackson *et al*, the study was designed to provide for the concurrent implementation of both qualitative and quantitative methods to gain a deeper understanding of the complex phenomena associated with communication about incurable illness, life expectancy, and treatment options. The results showed that many caregivers reported that they had not been informed by the physician that the patient's disease had become incurable, had never been provided with information on the life expectancy of the patient and that possible hospice admission had never been discussed with them. They also stated that the first discussion relating to the possibility that the disease might be incurable and to possible hospice referral only took place about a month before the patient's death. The open ended interviews however showed ambivalence in family caregivers' expressions on what they wanted to know and on the difficulty they experienced in accepting bad news. These findings then lead the authors to conclude that ineffective communication regarding end of life issues could be caused either by a reluctance of the physician to enter into discussions thereon with patients and care givers or in a reluctance of the family caregiver to be confronted with bad news.⁶⁰

Audrey *et al* also focused on communication by oncologists with their patients. They employed qualitative research methods to describe patients' experiences of palliative chemotherapy and whether the survival benefit of receiving such chemotherapy was discussed with them by their treating oncologists. The patients were interviewed before they saw their oncologists.

Thereafter, the consultation with the oncologist where palliative chemotherapy had been discussed was recorded and observed to capture non-verbal communication. The patients were then interviewed again at least once in the weeks that followed. Oncologists who consented to the recording and observation of consultations were also interviewed towards the end of the study. Thirty seven oncologist-patient consultations were recorded. Analysis of the recordings focused on the quantity of information regarding the survival benefits of palliative chemotherapy divulged by the oncologists to their patients. It was found that most patients were not clearly informed about such benefits. This could influence informed consent and decision making on further treatment. If oncologists only concentrate on the symptom relief and quality of life benefits of palliative chemotherapy and not on survival benefits, patients might assume an improvement in their overall survival, which might not materialise. It was recommended that oncologists, in their discussion of palliative chemotherapy with their patients, sensitively describe the benefits and limitations which must include survival gain. A positive outcome of this study was that participating oncologists acknowledged that palliative chemotherapy regimens were not necessarily the answer for the treatment of patients with advanced disease. Together with their patients they hoped for a better solution in the near future. However, by avoiding unrealistic expectations and by focusing their treatment decisions on current evidence, oncologists can improve their ability to assist patients in making informed decisions regarding treatment options.⁶¹

Friedrichsen and Milberg addressed the physicians' perspective regarding losing control when breaking bad news to patients with advanced cancer. The aim of this qualitative study was to evaluate all the problems experienced by physicians during communication with terminally ill cancer patients concerning the termination of tumor specific treatment due to incurability of the disease. The medical directors of ten clinics in one county in Sweden were requested to select physicians in their respective clinics for participation. This may be seen as selection bias as the medical directors may choose physicians who they think might be more appropriate for this particular study. Thirty physicians were interviewed during this study. However, the fact that only Swedish-speaking doctors were allowed to participate does affect generalisation of the results.⁶²

The physicians interviewed were asked to describe the way in which the information was presented to patients and to discuss what made the information positive or negative, what issues presented and how they dealt with it. They identified their fear of losing control, their behaviour and possible patient reactions as the main problems experienced during the provision, to their patients, of information on the transition from disease specific treatment to palliative care. However, due to the sensitive nature of the discussions regarding patients whose disease had become incurable, it would have been appropriate to mention possible referrals for counseling and support to those participants who might be in need of it.⁶²

It was apparent that an academic approach, thorough theoretical knowledge and a sound scientific background were important for a meaningful discussion of reasons for treatment decisions. Theoretical knowledge and experience, though, will not prevent emotional outbursts by patients during these conversations. These emotions should be recognised, acknowledged and legitimised by the physician and support should be offered. To be able to maintain emotional control physicians were advised to go through further training in clinical practice in palliative care and in spirituality.⁶²

It is clear from the above studies that communication with patients with advanced disease is a complex component of their treating oncologists' profession. Oncologists find it difficult to disclose information regarding diagnosis, prognosis and treatment response rate to their patients and have a fear of losing control while doing it. Providing information regarding survival benefits of palliative chemotherapy was also identified as a problem as well as delayed discussions of incurable illness, life expectancy and hospice referrals. Development of communication skills through training and experience, a holistic approach to patient care, further training in spiritual and palliative care as well as encouragement of positive attitudes towards patient communication are recommended. That will contribute to the improvement of patient-oncologist communication which is a critical determinant of the quality of advanced cancer care.

2.3.2 The patient's preference

Bad news is seen as any type of information which has the ability to negatively influence a patient's view of his future. It may consist of information regarding diagnosis, disease recurrence or progression or treatment failure in the oncology setup. Good communication skills are necessary when presenting this information to decrease patient distress. However, the majority of physicians do not have a strategy for the delivery of bad news and, based on expert opinion, most communication skills do not have a strong theoretical basis or take the patient's preference into account. Furthermore, communication features preferred by patients were associated with less psychosocial distress and improved patient satisfaction.

Fujimory *et al* performed a study on Japanese cancer outpatients. The aim of the study was to identify patients' preferences regarding the disclosure of bad news about their disease. The authors appropriately used a quantitative study design to assess descriptive data in order to explore the components of these patients' preferences and to find variables associated with communication style preferences. A survey was conducted to determine patients' preferences of communication styles of their physicians when delivering bad news. The design of the survey was based on previously conducted patient-consultant interviews, on a systematic literature review and on discussions amongst the authors. However, it was not mentioned whether the survey had been validated. The criteria for the inclusion of participants were well described. Yet, the fact that only patients able to speak and write Japanese were allowed to participate does affect generalisation of the results. Similarly, the fact that only those patients who were regarded by their physician to be capable to complete the questionnaire were chosen to participate, could be considered as selection bias. Nevertheless, the results were clearly described followed by a comprehensive discussion.⁶³

It transpired that the majority of patients preferred a communication style where both positive and negative information regarding their condition were given in a supportive manner. Continuation of physician care with a future treatment plan was important and vagueness was the least preferred. Physician-patient engagement was important, therefore, when bad news was delivered. Although most of the preferences of Japanese patients are similar to those of Western patients, some differences were noted. Consideration for the patient's family by the

physician, for instance, is regarded as very important by Japanese patients. This emphasised the importance of understanding an individual's communication preferences to improve patient-physician communication.⁶³

Hagerty *et al* conducted a study on 126 patients with metastatic disease whose disease had been diagnosed incurable six weeks to six months before recruitment, eliciting their preference for prognostic information. The literature review, which was comprehensive and up to date, showed that, although most of the literature pertaining to communication covered the breaking of bad news, not much guidance was available for physicians on how to communicate prognosis, especially in the newly diagnosed metastatic disease context. This led to a well formulated aim for the study, namely to determine the preference of metastatic cancer patients for prognostic information and to explore predictors of these preferences. A written survey was done to determine patient preference of prognostic information and the results were clearly set out.⁶⁴

The majority of patients wanted detailed prognostic information such as disease symptoms, treatment options and side effects, longest survival time with treatment, five year survival rates and overall survival. Although most patients preferred positive information, more than 65% of the patients also wanted less positive information about their disease. A desire for broader information such as how the disease would influence their daily lives was also indicated. From the results it was concluded that most patients with advanced disease wanted detailed information about their prognosis but preferred to negotiate the extent of the information and the timing of the communication. The results further highlighted the importance of recognising the patient's emotional needs and cognitions when discussing prognostic information.⁶⁴

Physician-patient communication can also become problematic when the patient becomes terminally ill. Yun *et al* performed a study to investigate the attitudes of cancer patient's as well as the attitude of their family members towards the diagnosis of a terminal cancer. They found in their literature review that patients often were not well informed when their disease had become terminal and when the aim of treatment had changed from curative to palliative. This information is important to enable patients and their families to take charge of their

circumstances and to make important life supporting decisions. They constructed a questionnaire for cancer patients and for families who have relatives with cancer. This questionnaire was to be used to determine the attitudes of cancer patients and their families regarding the diagnosis of terminal cancer. Although the questionnaire was based on previous studies regarding the disclosure of bad news, it was not mentioned whether it was validated. Patient and family members were not allowed to share information. Patients who were accompanied by family members were interviewed in a separate room. Thus, patients were prevented to answer according to family expectations.⁶⁵

An important finding was that 96.1% of the patient group wanted to be informed whether their disease became terminal. This differed significantly from the 76.9% of the corresponding proportion in the family group. More patients than family members wanted their physician to give this news and to do so immediately after the diagnosis was made. These findings should encourage physicians not to withhold information about terminal illness from their patients in an effort to protect them from the truth. Physicians must also take note that the patient and family unit may have different attitudes regarding disclosure of such information.⁶⁵

The above mentioned studies emphasised advanced cancer patients' needs for detailed information about their disease. It is important that this information contains both positive and negative facts together with a well structured treatment plan and must be conveyed in a supportive manner. Information should not be withheld to protect the patient. The physician should understand the individual preferences of the patient and recognise his cognitions and emotions. He should also consider the family of the patient when informing them about the patient's illness but should also realise that patient and family may have different needs for and attitudes towards such information.

2.4 Considerations regarding chemotherapy in advanced cancer patients

Indications for the use of palliative chemotherapy in patients with advanced disease are constantly on the rise. Benefits such as prolonged survival and quality of life for patients with chemo-sensitive tumors confirm that palliative chemotherapy should be considered as a treatment option in cases of incurable disease. However, to minimise harm, the challenge for

the treating oncologist is to balance the benefits of tumor response with the toxic side effects of the drugs. Factors that need to be reflected on in each palliative chemotherapy case are performance status, tumor sensitivity, survival prognosis, side effects profile and co-morbidities. As the disease progresses despite palliative chemotherapy, the survival benefits and symptom relief may be affected and the harmful effects of the treatment may increase. This may lead to recurrent hospital admissions and may even shorten life expectancy.⁶⁶ Thus, to allow his patients to die with dignity and to simultaneously improve their survival through palliative chemotherapy, the treating oncologists should evaluate continuation or cessation of chemotherapy with caution and should organise related healthcare resources appropriately.⁶⁷

Nappa *et al* hypothesised that at least one month of post treatment is needed to increase life expectancy. They analysed the data on all Swedish patients with epithelial cancer who passed away between 2007 and 2008 and who received palliative chemotherapy within a year of their death. One of their aims was to identify potentially harmful effects which may be caused by the administration of palliative chemotherapy during the last month of life. They found that patients who received palliative chemotherapy during their final month of life had a significant shorter length of survival, measured from the start of palliative chemotherapy to their death. Such patients also had frequent hospital admissions and died less frequently at home. However, it could not be concluded whether these harmful effects were a result of disease progression or were side effects of the chemotherapy. Nevertheless, these results emphasised the importance of assessing each patient individually before prescribing palliative chemotherapy. Guidelines may be useful to assist oncologists to determine if their patients are fit for more treatment and are likely to survive long enough to benefit therefrom.⁶⁶

Keam *et al* investigated the appropriateness of chemotherapy and care of advanced cancer patients near the end of their lives. They evaluated 298 Korean patients with metastatic cancer who died of their disease with regards to end of life care and chemotherapy received. A significant proportion of patients were found to have received inappropriate, aggressive chemotherapy up to the end of life. It was found that these patients also visited emergency rooms and were admitted to ICUs more frequently near the end of their lives. In addition, only

9.1% of patients whose treatment had been stopped were referred to hospice services. This could be due to the lack of proper hospice services and poor coordination between hospice programmes and hospitals in Korea. The fact that the study only represents a single centre in Korea does affect generalisation. Nevertheless the results lead to a comprehensive conclusion that the treating physician should continuously evaluate the appropriateness of prescribing chemotherapy to a patient with advanced metastatic disease and highlight the importance of the patient's early referral to support services to improve quality of care.⁶⁷

The effect of an aggressive approach to the administration of chemotherapy to advanced cancer patients in the final two weeks of life was also investigated by Saito *et al.* They identified 7879 Medicare enrolled patients over the age of 65 who, between 1991 and 1999, passed away after surviving at least three months after they had been diagnosed with advanced NSCLC. They found, in general, that receiving chemotherapy had been associated with a survival benefit of two months. However, patients who had received chemotherapy in the final two weeks of life experienced no survival benefit. They were also much less likely to receive hospice care, and then only for three days or less. This notwithstanding, prescription of chemotherapy for patients with advanced disease is still recommended, even without a survival benefit, if it is indicated that the treatment will improve the quality of life of the patient. The findings of this study suggested that the aggressive approach of chemotherapy near end of life not only had little effect on survival but also had a negative effect on quality of life. It is therefore imperative that oncologists base their treatment decisions on the circumstances pertaining to each individual patient, considering both expected risks and benefits of chemotherapy.⁶⁸

Major advances have been made over the past 15 years in the treatment of patients with advanced NSCLC. Additional active agents made second and even third line treatment options for NSCLC patients a common practice. However, overall survival increased with only 1.5 to 2 months with these treatment advances. This put the patient at risk of receiving chemotherapy near the end of life. Murillo and Koeller conducted a retrospective chart review of deceased advanced NSCLC patients who received chemotherapy to characterise the chemotherapy given near end of life in the community oncology setting. They found that the majority of patients

received first and second line chemotherapy while 26% received third line, 10% received fourth line and 5% of patients received fifth line chemotherapy or greater. Of these patients 43% received chemotherapy within one month of death and 20% of patients within two weeks of death. These findings demonstrated an increase in the use of chemotherapy near the time of death in patients with NSCLC. The availability of more treatment options, the inability of physicians to predict the life expectancy of patients with NSCLC and possible pressure by the patient or his family demanding additional treatment, based on information obtained from the internet or other sources, may all contribute to these prolonged chemotherapy treatments.⁶⁹

The choices of treatment for advanced cancer patients at the end of their lives have become more complex. This is due to the increase in the variety of anticancer treatments, higher expectations of treatments, less severe side effects of therapy and improved supportive care. As a consequence, these complex choices can markedly influence the lives of the patient and his family members as well as the cost of the patient's healthcare. Matsuyama *et al* conducted a search of relevant literature published from 1980 to 2006 in a number of countries. The aim of this search was to determine the availability of information regarding prognosis and treatment efficacy to advanced cancer patients and to establish how these patients arrived at decisions on chemotherapy and other types of supportive care. They concluded that patients with advanced cancer were inclined to opt for chemotherapy even if only a minor health benefit might materialise. These patients were also found to be less concerned about adverse effects of treatment than their healthcare providers. It was unclear if the provision of information regarding prognosis and treatment choices would have affected the decision making process. Although patients indicated a desire to be provided with such information most patients did not receive it. These findings may explain the increased use of chemotherapy in advanced cancer patients near the end of life. The authors further found that no decision aids were available to assist metastatic cancer patients to make their treatment choices. The provision of unbiased, honest information regarding prognosis, treatment options, outcomes and consequences as well as decision aids would have assisted advanced cancer patients with informed decision making.⁷⁰

It was clear from the studies and reviews referred to above that patients with advanced cancer received more palliative chemotherapy near the end of their lives. Such inappropriate treatment caused frequent hospital admissions, less hospice referrals and even a shorter length of survival from the start of palliative chemotherapy to their death. Reasons for this type of treatment could be the availability of more treatment options, pressure exerted by patients and their families, inadequate information regarding prognosis, outcome and treatment side effects given by the treating oncologists and the patients' willingness to undergo chemotherapy even if the outcome would have little benefit for their health. This information emphasises some patients' urge to avoid death at any costs and the importance that the treating oncologists guide their patients in making informed decisions by providing adequate information regarding disease prognosis, treatment outcome and side effects.

2.5 Attitudes towards advance directives

The development and implementation of advance directives are regarded as a basic aspect of medical care and are widely advocated by many medical societies. It is accepted that it will assist the patient, his family or loved ones as well as his treating physician to take decisions regarding his treatment and care when he (the patient) is prevented by circumstances caused by his illness to take such decisions. In this way his autonomy near the end of his life is preserved. Especially patients suffering from advanced malignant disease, who will inevitably be confronted with decisions regarding the end of their lives, will benefit from the use of advance directives.⁷¹

Kierner *et al* assessed the attitudes towards and wishes regarding advance directives among hospitalised patients suffering from advanced malignant disease. Patients who participated in the study were verbally given information regarding the purpose of advance directives and on how such a document should be compiled. They were then asked if they were interested in drawing up an advance directive. Patients who were not interested were asked to complete a questionnaire to determine their reasons for not showing interest.⁷¹

Despite all the benefits associated with advance directives only a very small percentage (10%) of these patients showed any interest therein. The main reasons given by the patients for their

disinterest were that the time to consider such directives was inappropriate; that they were too young and too optimistic to contemplate such directives; and that they had full confidence in the ability of their treating physicians to take such decisions when necessary. Patients who agreed to consider advance directives showed a high incidence of depression and anxiety which were associated with a poor performance status. The reason for this was however unclear. A possible explanation for the patients' depression was given that the issuing of advance directives could have brought them in touch with the reality of their terminal disease. Alternatively it could also be disease progression which could elicit signs of anxiety and depression. Nothing was mentioned, though, about steps that were taken to refer these patients whose depression and anxiety were identified during the study, for proper management of their symptoms. Furthermore, hospitalised patients suffering from advanced disease are usually seen as vulnerable participants in medical research due to their physical condition. Additional precautionary measures should be taken, therefore, to ensure that these patients were competent and fit enough for participation and informed consent. Ethical considerations and measures to ensure suitable participants were not mentioned, however. The only criteria mentioned for exclusion was unconscious patients.⁷¹

A similar study was undertaken by Van Oorschot *et al.* Oncology patients who were receiving radiotherapy treatment were provided with and completed a standardised questionnaire. In contrast with the findings of Kierner *et al*, the attitudes of patients towards advance directives in the Van Oorschot study were found to be positive. At the time of the survey 23.6% of the patients had already signed an advance directive while 53.3% showed a real interest in compiling and signing such a directive. Only 9% did not want to sign an advance directive while 4.9% were not familiar with the concept of advance directives. Patients who showed interest in advance directives considered that it might facilitate the physician's decision making process and reduce the burden on their relatives. In addition, every second respondent acknowledged that advance directives would rather enhance the interaction between patient, relative and physician than providing rigid prescripts for a concrete situation. It is important, therefore, that physicians familiarise themselves with the consultations and procedures required to produce

advance directives. Such directives could not only facilitate later decision making but could also improve the physician-patient relationship and communication.⁷²

Guo *et al* examined the prevalence of advance directives among oncology patients with malignant spinal cord compression. The data of 88 patients with spinal cord compression presenting for rehabilitation consultations at a cancer centre in the USA were retrospectively reviewed with regards to advance directives. Although patients with malignant spinal cord compression have a well documented median survival of 3 to 6 months, only 20 patients (23%) reported having a living will; 27 patients (31%) reported the existence of an identified healthcare proxy; and 10 patients (11%) had a “do not resuscitate” order. Ozanne *et al* also found in their study of the existence of advance directives in patients with metastatic breast cancer that the majority of patients did have advance directives and had had discussions with their family members or friends about end of life decisions. However, only a minority of these patients shared this information with their oncology care providers. These findings emphasised the lack of urgency among these patients to have an advance directive despite their short median of survival. This may be an indicator of delayed palliative care and sub-optimal doctor-patient communication regarding end of life goals and terminal care. Physicians should grasp the opportunity to discuss advance care planning and end of life care when their patients present with malignant spinal cord compression or metastatic disease. This will give patients and their families time to process the information, improve doctor-patient communication and, eventually, to improve end of life care.^{73,74}

Advance directives play an integral role in the management of patients with incurable disease. Although the implementation thereof often is perceived as a difficult issue to manage, the positive outcomes could enhance the quality of the patient’s end of life care. Advance directives improve doctor-patient communication and prepare the patient and his family for what lies ahead. It reduces the fears, stress and uncertainties of family members, patients and oncologists. When the inevitable occurs everyone is on equal footing as far as management and care are concerned. Kwon *et al* also found in their study of the advance directives prepared by terminal cancer patients or their family members that most patients stated that they did not

want to be resuscitated or to have their life prolonged by invasive, painful procedures. They were prepared to undergo supportive measures that would reduce pain and improve quality of life regardless of whether it would prolong life or not.⁷⁵ In their study regarding the satisfaction level associated with the completion of advance directives by patients with advanced disease Pautex *et al* further established that participants showed lower anxiety and depression levels after completion of the directives.⁷⁶

It is important, therefore, that patients with advanced disease should be made aware of the need for and be encouraged to complete advance directives. Pautex *et al* described that this will lead to a reduction of fear and to an improvement of communication between patients, proxies and health professionals and, ultimately, to an enhancement of the quality of end of life care.⁷⁶

2.6 The palliative care team approach

Often care for patients with advanced disease is described as sub-optimal.⁷⁷ Patients and families identified inadequate pain relief and symptom control as well as unnecessary invasive life sustaining interventions at the end of life as major shortcomings. In the same vein information regarding prognosis and treatment options is also frequently perceived as insufficient.⁷⁸ It is believed that these shortcomings in end of life care can be countered by making use of interdisciplinary palliative care teams. Such teams are able to provide a full spectrum management of the patient and his family's physical, psychosocial and spiritual needs while treatment is directed in accordance with the patient's needs and wishes.⁷⁹

Gade *et al* conducted a multicenter, randomised controlled trial on inpatients suffering from a life limiting disease. They conducted a comprehensive literature review which accentuated the suboptimal standard of care for patients with advanced disease and the limited evidence of positive effects which an inpatient palliative care facility could have on these patients. Hence, the aim of their study was set out as follows: To measure the impact of an interdisciplinary inpatient palliative care consultative service on symptom control, patient satisfaction and on quality of care.⁷⁹

They also investigated the costs of healthcare services received during the period of six months after the patients' discharge from hospital. These costs were compared with the costs of normal inpatient hospital care. They found that the patients managed by the inpatient palliative care team reported greater satisfaction with their care experience and with the communication with their care providers. In addition, they had less ICU referrals on readmissions, longer periods of hospice stay and a higher incidence of preparation and acceptance of advance directives. The costs of their post-discharge healthcare were also lower. There were no differences in overall survival. These findings provided evidence which confirmed the positive impact of palliative care consultations on the levels of patient satisfaction with care, on hospice utilisation and on healthcare costs.⁷⁹

Jack *et al* investigated 100 cancer patients who had been admitted to hospital for symptom control. Fifty patients received intervention from a hospital based palliative care team while the remaining 50 received standard hospital care. The impact of care on symptom control was researched by using the Palliative Care Assessment symptom assessment tool. This tool had been extensively assessed in terms of validity and reliability. This assessment was repeated on three occasions. As in the case of the trial conducted by Gade *et al*, both groups showed improvement in symptom control. However, the group in which the palliative care team intervened showed better symptom control, particularly for pain and anorexia. Jack *et al* conducted further studies on how intervention by hospital palliative care teams improved the insight of cancer patients into their disease. Again, in a group of 100 cancer inpatients, 50 patients who received intervention from the palliative care team were compared with 50 patients who received standard hospital care. This comparison was also repeated on three occasions. The patients' self reported understanding of their disease was tested. It was found that those patients who received input from the palliative care team showed greater insight in their diagnosis and prognosis when compared with the patients who received standard hospital care. It was concluded from the findings of both studies that the interventions by the palliative care teams not only improved symptom control but also that the team members had an in-depth knowledge of the cancer journey. Further, this knowledge was associated with specific

skills to communicate, treat and provide support and, hence, enabled team members to comfortably and effectively care for a dying patient.^{80,81}

An important central component of palliative care is teamwork. Establishing teams well versed in palliative care can be a challenging venture. Junger *et al* studied the factors which the members of a team in a palliative care unit associated with success and regarded as necessary to ensure positive team work results. Members of the palliative care team of the University Hospital of Aachen were subjected to semi structured interviews one year after the team was formed. They found that communication, team philosophy, commitment and work climate were crucial elements necessary to enhance cooperation within a team. Communication was not only regarded as information exchange to keep team members up to date and thereby enhancing work flow. The informal exchange of ideas, subjective perceptions and speculations as well as humor were viewed as essential elements for effective team functioning. The need for openness and flexibility among team members, opportunities to discuss goals as well as the negative impact of unclear goals and procedures were new aspects which surfaced during this study. Commitment, sustained performance and the experiencing of work satisfaction by team members were shown to be strongly associated with an optimistic approach by the team and strong identification with the team's goals.⁸²

The above mentioned studies showed that involvement of a palliative care team in the management of patients with advanced cancer had a positive impact on patient care and provided the treating oncologist with much needed support. It improved patients' satisfaction with care and symptom control and resulted in decreased health care costs due to fewer hospital admissions and earlier hospice referrals. In addition, the improved communication regarding diagnosis and disease prognosis led to a better insight by the patients in their disease.

Therefore it is strongly recommended that oncologists should make use of a palliative care team in their units to share the load of dealing with all the clinical problems and complex psychosocial issues associated with patients suffering from advanced cancer. Communication between members of the palliative care team and the treating oncologist together with clear

goals, commitment and a positive work climate is crucial for the team to function well and enhance patient care.

2.7 Oncologist burnout

Managing patients suffering from an advanced incurable disease can cause a great deal of stress to their treating oncologist. Burnout amongst oncologists and oncology healthcare workers is a common phenomenon and is well documented in the literature.

Allegra *et al* conducted a survey to determine the level of burnout in the oncology community in the United States. Their literature review focused on the occurrence of stress and burn out in the medical profession and described previous surveys performed on oncologists to determine the presence, cause of and remedies for burnout. Their aim was to reassess the level of burnout amongst oncologists in the U.S.A and to understand any changes that may have occurred in recent times. Participants were given the opportunity to complete the surveys via email or at live meetings. Seven thousand seven hundred and fifteen medical and hematologist oncologists participated in the study but only 22.6% completed the survey. They were distributed over the major geographic areas of the U.S.A and spent the major portion of their work on patient care activities. Overall, 61.7% of the participants stated that they were experiencing feelings of burnout with the primary three signs being frustration, emotional exhaustion and lack of job satisfaction. The main causes for burnout were reported as being overworked, lacking time away from work and financial remuneration concerns. Participants considered more time away from office, the attendance of medical conferences and fewer patients to be the main remedies to counteract burnout. Interestingly, neither the area of the country where the participants worked nor the number of partners in the oncology practice had any influence on burnout. The results of the survey indicated that, although stable, the rate of occurrence of burnout among oncologists in the U.S.A is still perceived as high. Oncologists need to be encouraged to increase their time away from work as well as to attend professional meetings to increase professional pursuits. By alleviating burnout amongst oncologists, the quality of care provided to patients will also be enhanced.⁸³

The above mentioned findings of Allegra *et al* more or less correlated with the results of a similar survey which had been conducted by Whippen *et al*. One thousand physician subscribers to the Journal of Clinical Oncology were randomly selected to participate in the survey. Fifty six percent of the respondents reported experiences of burnout in their profession. Similar to the findings of Allegra *et al*, the causes of burnout were identified mainly as a lack of time away from work and, secondly, as frustration. A feeling of failure, a heavy work load, remuneration issues and the administration of palliative or terminal care were also described as strong contributing factors to burn out. More vacation and the need for more personal time away from work were indicated to prevent burnout. Due to the high response rate to the questionnaire (60%) and the high incidence of burnout among the respondents, the authors concluded that more research on this topic was necessary.⁸⁴

Dougherty *et al* found in their survey of 60 oncology personnel members at an inpatient palliative care unit that 63% of the staff reported high levels of stress experienced at work. However, the small sample size and the fact that the survey was done at a single palliative care unit does limit generalisation of the results. Reported stress levels were determined by the indication of stress symptoms on the completed questionnaires, such as being emotionally drained and experiencing feelings of reduced accomplishment. These questionnaires were not validated, though. The main causes of work related stress were high workload, inadequate time to grieve the death of patients, insufficient institutional support in a stressful work situation, lack of resources and the inability to choose one's workplace. More than half of the respondents believed that work related stress had a negative impact on patient care and more than 80% considered that high levels of work stress affected their ability to give emotional support and compassionate end of life care. Ethics rounds with a clinical ethicist, yearly staff retreats and morbidity and mortality meetings to discuss and reflect on difficult cases were some suggestions made to reduce work related stress.⁸⁵

Burnout can seriously affect the treating oncologist's personal health and his interaction with his patients and colleagues. If left untreated, it could have a significant negative impact on the quality of medical care provided. Swetz *et al* conducted a qualitative online survey of 40

hospice and palliative care physicians, practicing in the United States to determine the strategies they employ to counteract burnout and to improve job satisfaction. The most common strategy reported was enhancement of physical well being followed by supportive professional relationships, transcendental perspective and spirituality, communication with others, hobbies, clinical variety, personal relationships and personal boundaries. Sufficient time away from work, passion for one's work, humor, laughter and realistic expectations as well as remembering patients who passed away were also suggested.⁸⁶ Italia *et al* found in their study of doctors and nurses working in an adult and pediatric oncology unit, that burnout syndrome which exists among the staff can be effectively treated with art therapies.⁸⁷ Granek *et al* interviewed 20 oncologists to gather suggestions on how their units or institutions could support them to deal with the loss of patients. Suggestions that were made included training and provision of information, acknowledgment and validation of grief, institutional psychosocial support and vacations and sabbaticals.⁸⁸

Working in cancer care can be extremely stressful due to the frequent exposure to pain and suffering of patients who, due to the fact that their disease has become incurable, are in the process of dying. Surprisingly studies have shown that palliative care staff experiences the same psychological distress as staff working in other medical specialties. Yet, the latter experiences less burnout.⁸⁹ Ablett *et al* conducted a qualitative study to describe the work experience of palliative care nurses to identify those personal traits which enable them to be resilient and maintain a sense of well being while caring for patients with advanced disease. Ten palliative care nurses (nine female and one male) were recruited from a hospice in North West England. The fact that many of the hospice workers knew the first author as a clinical psychologist may be regarded as researcher bias. The results of the study produced 10 themes which the nurses used to describe their work experience. These themes showed a high degree of commitment and sense of purpose towards their work. Interpersonal factors such as resoluteness and a sense of coherence were identified as strong promoters of resilience which enabled staff to manage the stress associated with working in palliative care. To promote resilience the training and support of staff to develop resoluteness and a sense of coherence were suggested.⁹⁰

According to this literature review burnout is a real and serious condition which is common amongst oncologists, yet less common amongst palliative care workers. It affects the physical strength and mental health of treating oncologists which can lead to poor interaction with staff and patients. Ultimately it results in a deterioration of quality of care. It is crucial that the treating oncologist should acknowledge warning signs of burnout, such as frustration, emotional exhaustion and feelings of worthlessness, and should be acted on appropriately. Support systems should be in place, relevant information should be readily available and special rounds and meetings pertaining to difficult cases should be regular events in each oncologist's treating unit. In addition, personal strategies such as time away from work, physical exercise, hobbies, art, humor, spirituality and making time to remember patients who passed away should be applied to prevent and treat burnout. By applying appropriate strategies and by utilising institutional support systems to manage and prevent burnout, the personal wellbeing and job satisfaction of the treating oncologist could be enhanced. This will undoubtedly lead to an improvement in the quality of care provided.

2.8 Work done in South Africa

There are few South African studies on palliative care for patients with advanced cancer. The management of patients with life limiting disease in South Africa and Uganda was investigated by Selman *et al*. The quality of life of patients with incurable, progressive disease, who received palliative care were researched and described.⁹¹ They also explored the information needs of patients with progressive, life limiting disease and their family members.⁹² Harding *et al* also performed a study on advanced cancer patients in South Africa and Uganda but focused on the determination of symptom prevalence and burden amongst patients.⁹³ They found that pain management and psychosocial matters were the most prominent issues and that psychosocial and spiritual well being and pain control was regarded as equally important determinants of quality of life. Lack of information given to patients and their family members were identified as a problem too. Harding *et al* also did some work on the challenges of conducting research in Africa⁹⁴, on palliative care in the African context⁹⁵ and on assessing and improving palliative care in South Africa.⁹⁶

Gwyther, who participated in the studies done by Selman *et al* and Harding *et al* in Uganda and South-Africa, reported on the status of palliative care in South Africa.⁹⁷ Sebuyira *et al* commented on the Cape Town palliative care declaration regarding home grown solutions for Sub-Saharan Africa.⁹⁸

All the above mentioned studies concentrated mainly on the field of palliative care given to patients with advanced, life limiting disease in Sub-Saharan Africa.

2.9 Conclusion

Managing patients with incurable disease is an integral and complicated aspect of an oncologist's daily profession. Apart from the difficult clinical oncological issues treating oncologists are regularly confronted with, complicated additional challenges such as dealing with complex psychosocial issues associated with the treatment of distressing physical symptoms experienced by their patients, with having difficult discussions regarding treatment side effects and disease prognosis, with decisions whether to continue or cease treatments and discussing advance directives with patients and their families. As a consequence oncologists are continuously being exposed to possible burnout syndrome.

As outlined in the above literature review, numerous studies have been conducted on the complicated aspects associated with the treatment of patients with advanced cancer. Some of the worrying factors identified in the literature are the inadequate training of oncologists in the field of palliative care, their inability to identify psychosocial distress in cancer patients and the fact that they find it very difficult and are sometimes unable or unwilling to disclose information regarding diagnosis, prognosis and the likely responses to treatment to their patients, even if such information is requested. Furthermore, it is indicated that more patients with advanced cancer receive inappropriate palliative chemotherapy near the end of their lives, that there is a general lack of urgency regarding the development of advance directives by patients and that there is a high incidence of burnout amongst oncologists. The complexities of these non-clinical issues which are inevitably involved with the caring for the terminally ill cancer patient constitute an important component of the oncologist's profession. It needs to be further

researched to facilitate a better understanding thereof. The formulation of strategies to mitigate these difficulties will eventually improve job satisfaction as well as quality of care.

As outlined in the literature review, numerous studies have been conducted on all the important individual aspects associated with the management of patients with an incurable disease. However, the holistic management of such patients in a private oncology institution has been inadequately researched and is to some extent lacking in South Africa.

Therefore, the researcher will not only focus on the integration of palliative care in an oncology practice but also on other important aspects that forms an integral part of the management of patients suffering from incurable cancer. These aspects include communication with cancer patients and their family members, the use of advance directives, the implementation of a multidisciplinary approach, factors influencing treatment decisions and the difficult demands faced by an oncologist in private practice.

CHAPTER 3: Research methodology

3.1 Introduction

The researcher decided to conduct his study on the current practices of oncologists working in a private oncology clinic in South Africa and who are managing patients with solid tumours which no longer respond to anticancer treatment. The important individual aspects of the management of patients with incurable cancer have been well researched and documented, as outlined in chapters 1 and 2 above. However, not much work has been done on the holistic treatment of these patients, especially in the private oncology sector in South Africa. A concise description of the research methodology employed to conduct this study is set out below.

3.2 Rationale for the study

Patients suffering from advanced disease which no longer responds to anticancer treatment present their treating oncologists with major stressors. These may range from the management of distressing physical symptoms to complex psychosocial issues. In addition, oncologists in the private sector are faced daily with exacting challenges such as the high demands of patients and their families, the increasing pressure to administer more patients with lucrative anticancer treatment and with difficult discussions regarding disease prognosis, cessation of anticancer treatment and advance directives. Eventually the combined effect of all of these factors affects the quality of care provided and may lead to possible burnout of the treating oncologists. This set of circumstances commonly prevailing within the private oncology sector prompted the undertaking of this study.

3.3 Aim of the study

To evaluate the current practices followed by oncologists in the private sector of Cape Town, South Africa, in the management of patients with advanced cancer which no longer responds to anticancer treatment and to identify the needs associated with such management.

3.4 Objectives of the study

3.4.1 To identify the current practices followed by oncologists in the private oncology sector in South Africa in the management of patients who no longer respond to anticancer treatment.

3.4.2 To identify the information and training needs of these oncologists which must be met to enable them to effectively manage these patients.

3.4.3 To identify support services needed by oncologists who manage patients with progressive and terminal illness.

3.4.4 To identify processes and procedures that may contribute towards the improvement of care to patients with incurable disease in private oncology centres.

3.5 The study design

The researcher selected a descriptive qualitative study for data collection through in-depth semi structured interviews with private oncologists.

3.6 Philosophical background

The aim of the study is to evaluate the treating oncologists' experiences with patients whose diseases have become incurable. By following the flexible and explorative methods associated with qualitative research, a deeper understanding of such experiences and of the meaning the oncologists attribute thereto can be developed. Furthermore, qualitative research draws from the philosophy of phenomenology in that it focuses on the structures of experiences of phenomena and the interpretation thereof and, thus, provides a holistic view of the phenomena under investigation. This phenomenological approach is well suited to explore affective, emotional and often intense human experiences which would be appropriate in this particular study. On an ontological level, qualitative perspective states that there are multiple realities or interpretations of a single event, in this case, the oncologists' experience of the management of patients with advanced disease. Knowledge can be constructed adequately from these experiences through the use of qualitative research methods. During the study attention will be focused rather on the building of new theories or concepts regarding the experiences of the treating oncologists than on the deductive testing of current hypotheses. Therefore, the process will be inductive, which is a typical important characteristic of qualitative research. The findings of the study will be presented by means of a rich descriptive narrative which is also associated with a qualitative research design.¹⁰⁰

3.7 Study site

Five satellite units of the private oncology company, GVI Oncology (GVI), were used by the researcher as study sites. These satellite units are situated in the Western Cape Province. They are the Rondebosch Unit in Rondebosch, the Vincent Pallotti Unit in Pinelands, the Panorama Unit in Parow, the Cape Gate unit in Brackenfell and the Vergelegen Unit in Somerset West.

3.8 Study population

The study population comprises radio-oncologists who are managing patients with solid tumors and who are attached to private South African oncology institutions based in Cape Town.

3.9 Sampling method

The researcher opted for a non-probability, purposive sampling method to recruit appropriate participants in the private sector that would render satisfactory data regarding the management of patients with incurable cancer. To enable purposive sampling, the researcher recruited his participants according to the following inclusion criteria:

- Participants must be qualified radio-oncologists.
- They must be actively practicing in the private sector in South Africa.
- They must have at least four years of clinical experience working as radio-oncologists in the private sector. The researcher regarded four years as adequate for an oncologist to have gained sufficient experience in the management of patients with incurable disease.
- Patients with solid tumors must be their main scope of treatment.
- They must be able to understand and speak English.
- They must be willing to undergo a face-to-face interview with the researcher.

The researcher submitted a request for permission to conduct this research project to GVI Oncology (see appendix A). A copy of his research proposal as well as proof of ethical approval (see appendix F) of the project was attached to this request. The researcher received permission per email (see appendix D) from the research committee of GVI Oncology to perform his study at the requested treating units.

3.10 Recruitment

Oncologists who were consulting at the selected treatment units and who fitted the inclusion criteria were approached and invited by email to participate in the study (see appendix B). After confirmation of their intended participation had been received, also by means of an email, a 30 minute appointment at a convenient time was booked with each oncologist's secretary to conduct the interview. All the oncologists who were approached were willing to participate and gave informed consent therefor. Although no incentives were offered to participate in the study, the researcher did, however, give each participant a small gift of appreciation for their time after the interview had been completed.

3.11 Sample size

The researcher estimated that 15 participants would be required to obtain sufficient data regarding oncologists' experiences with patients with incurable disease. The researcher regarded this number of participants as adequate as data saturation was experienced after interviewing 15 participants. After the 15 interviews the collected data did not shed any new light on the issue under investigation. Therefore, the sample size was large enough to ensure that all the important perceptions of the studied issue were covered. A larger sample size could have produced repetitive data which eventually could have become superfluous.

3.12 Data collection

The research protocol proposed face-to-face, in-depth interviews to collect data from the participating oncologists about their experiences regarding the management of patients with incurable disease. These interviews were mainly semi-structured but also contained a structured part which provided for the collection of sociodemographic data from the participants.

3.12.1 Data collection tool

An interview guide (see appendix C) was drafted which contains topics which have a bearing on the research theme. The guide was developed by the researcher in the light of the literature reviewed in chapters 1 and 2 above, after consultation with colleagues, in view of the researcher's own clinical experience in the private sector and after discussing the interview guide with his supervisor.

The first part of the interview guide consists of factual, sociodemographic type questions which were used to initiate the interview. The information required included the sex of participant, age of participant, clinic where the participant is working, number of years practicing as a private oncologist, tumor specialty and percentage of the participant's patients who receive advanced or palliative treatment.

The second part of the interview guide deals with important aspects of the treating oncologist's management of patients suffering from incurable cancer. Each topic is presented as a general, open ended question followed by a list of probes, areas or issues associated with the topic that were to be explored by the researcher during the interviews. Topics that were addressed in this study included the oncologist's experience of the management of patients with advanced disease, the oncologist's communication skills, factors influencing treatment decisions, the use of advanced directives, the palliative care team approach and oncologist's burnout. These topics emerged during the literature review as themes regularly associated with the oncologist's management of terminally ill cancer patients. The literature review also revealed that numerous articles have been written on these topics, which are indicative of their importance. The topic guide concluded with a section pertaining to the support necessary for patients with advanced disease. Some recommendations aimed at the improvement of the services to be rendered to such patients were also included.

3.12.2 Data collection procedure

After ethical approval and permission from GVI to perform the research had been received, the researcher approached oncologists who met the inclusion criteria with requests to participate in the study. This was done by means of an email in which the purpose of the study was explained and ethical approval and GVI's permission that the study may be conducted at the oncologist's treatment unit were confirmed. The researcher started by first approaching oncologists at his (the researcher's) own treatment unit, namely Rondebosch, followed by oncologists working at Vincent Pallotti, Panorama, Cape Gate and Vergelegen treatment units. After each oncologist had expressed in writing willingness to participate in the interviews, appropriate time slots of 30 minutes were booked with each oncologist's secretary. Thereafter

the researcher met the participating oncologists in person in his/her treatment unit on the allocated time of the interview. The meeting took place in the oncologist's consulting room.

At the commencement of each meeting with a participant, the researcher introduced himself and his workplace and outlined the aims, objectives and anticipated content of his study. The participant was informed that the interview would be performed in English and that it would be digitally recorded. The participant was further assured that there is no right or wrong answer and was encouraged to give as much information as he/she considered appropriate, welcoming examples from his/her clinical experiences. The participant was assured of the confidentiality of all information given and of his/her identity. However, some personal details of the participants such as age, gender and years experience in oncology needed to be disclosed for the purpose of the study. The interview could be stopped at any time at the request of the participant and the estimated duration of the interview would not exceed 30 minutes. The participant was informed that the study results would be published as an article in a medical journal and that he/she would receive a copy of it once the study would have been completed.

After discussing all the aspects associated with the interview process, the participant was given an opportunity to ask questions to clarify uncertainties. Thereafter each participant was provided with a consent form (see appendix E) and was asked to sign informed consent before the interview was started. The consent form was counter signed by the researcher as well as a witness from the clinical team. The completed consent forms were scanned and stored in the researcher's password protected computer.

After the preliminary procedures outlined above had been dealt with, the interview was proceeded with and digitally recorded by using an unobtrusive dictation recorder. Only the researcher and participant were present, thus ensuring privacy and confidentiality. The interview started with predetermined structured questions regarding sociodemographic information of the participant. This was followed by open ended questions and probes using the interview guide as reference. Care was taken not to lead the participant to certain conclusions.

The semi-structured interviews were introduced with a request for basic descriptive information regarding the participant's experience with the management of patients suffering from incurable disease. The information gathered from this question laid the foundation for further questions to access the participant's experience and opinions regarding the study topic.

Initially the researcher depended rather heavily on the guide to perform the interview. However, the researcher soon became comfortable and allowed the interview to run its course with only a few references to the interview guide to make sure all questions had been covered. The average duration of the interviews was approximately 16 minutes.

After the interviews, verbatim transcriptions of the digitally recorded interviews were stored on the researcher's password protected computer. These transcriptions will be submitted to the Faculty of Health of the University of Cape Town where it will be archived for audit purposes. Personal transcription of the interviews by the researcher enhanced his knowledge and understanding of the information obtained and assisted him to identify which information was relevant. The recorded interviews will be destroyed soon after completion of the study.

Although most of the interviews went smoothly without any major problems, the researcher did experience some difficulties during the data collection process. The oncologists' overloaded work programmes made it difficult to book appointments for the interviews. Appointments also had to be limited to 30 minutes slots to accommodate the oncologists' work schedules. Some interviews were even cancelled and rescheduled at short notice which seriously disrupted the researcher's work plan. Three interviews were interrupted by telephone calls which the oncologist had to take and the recording microphone was faulty during one interview. The problem was restored but the interview had to be re-recorded. The researcher also had difficulties to accommodate interviews with oncologists not located at the Rondebosch unit in his working schedule.

All oncologists requested to participate in the study enlisted and all interviews were completed.

3.12.3 Data analysis

The researcher made use of a thematic analysis method to analyse the collected data. The data analysis was done in combination with the data collection. Each interview was transcribed by the researcher directly after each interview had been performed. This enabled the researcher to enhance his recollection of the collected data while reviewing the interview material to identify tentative themes or categories as well as to refine questions to improve the interview process and the quality of data collected. The researcher identified six main themes during the transcription process using the process of coding as well as using the topic guide of the semi structured interviews as a reference. Based on his work experience, the researcher identified these themes as important and relevant topics which are generally associated with the management of patients with advanced disease. The responses given during the interviews clearly confirmed that the participating oncologists also regarded the themes as important and relevant.

The process of coding was repeated after all the interviews had been completed in search of other themes that would serve as subcategories. Categorisation continued until all relevant sub themes were identified and labeled. These particular themes were presented by abbreviated descriptive codes. A coding list which contains the symbol for each code, its name as well as a definition for each code was compiled. Colleagues, which included the practice social worker and medical officers together with the researcher's supervisor, were requested to review the main themes and subthemes for credibility.

The researcher used a basic word processing software namely MS Word as well as Microsoft Office Excel and adapted it to manage and analyse his qualitative data. All the themes and subthemes together with relevant quotes from the interviews were copied from the word documents containing the interviews and pasted on a Microsoft Office Excel sheet. This enabled sorting of the data which, in turn, facilitated description of the themes and subthemes. The Department of Family Medicine at the University of Cape Town accept it as appropriate practice, that the particular spreadsheet, together with all the word documents containing the transcribed interviews as well as the recorded interviews, is stored on a password protected

computer and is available for audit if required. These data must be stored for a minimum period of five years after which they will be deleted.

Conclusions were formulated after studying the particular coded themes as well as any patterns and connections within and between them, and bringing them all together. These conclusions were brought into context with the main theme of the study with a descriptive, narrative approach, after interpretation thereof in light of the literature research. A network display was used to visualise the findings. This display will serve as the conceptual framework for the study. Recommendations were made after the conclusions had been formulated.

3.13 Researcher reflexivity

As an oncology medical officer in a private clinic of this nature in South Africa, the researcher has witnessed firsthand the difficulties and shortcomings associated with the management of such patients. The researcher realised that there is a need for an evaluation of these practices. Such evaluation may stimulate interest which may lead to the improvement of the quality of care rendered to patients with incurable cancer.

According to the researcher's work experience the focus of cancer care in the private sector is primarily on evaluation, staging and the initiation of lucrative anticancer treatment. Seemingly, palliative care and supportive treatment do not receive the attention they deserve. After conducting this research project on oncologists in the private sector the researcher were able to determine the validity of his view. In qualitative research, the researcher brings his own experience and perspectives to the research; part of the research process is to hold an awareness of one's own bias as a researcher and to acknowledge this in the analysis and reporting of research. For this study, the researcher was aware that working as a medical officer in the same field and for the same company as his study population could put him at risk of projecting his own beliefs and values on the study material and manipulate the findings to suite his views. The researcher therefore gave a thorough explanation of the contents of the topic guide and emphasised his supervisor's involvement to improve objectivity in data collection. All interview recordings and transcripts are also available should there be any

dispute regarding the authenticity of the collected data. Potential bias was also considered during data analysis.

The study design was of a qualitative nature which comprised interviews with the participating oncologists during which researchable questions were asked. By combining explorative interviews with qualitative interviews the interviewer were able to identify important variables in this particular area of research. Further exploration of these identified variables through penetrating questions led to the development of new concepts or hypotheses regarding the relevant theme which, in turn, may require additional investigation.⁹⁹ After each interview with a participant, the researcher studied the contents thereof to identify aspects that need to be altered to improve the interview process. The questions were reviewed to determine if they were judgmental or leading and their formulation was reviewed where necessary to enhance the generation of information. The interview was also examined to determine whether the participant had been unduly interrupted by the researcher or had been allowed sufficient time to formulate his comments. In addition, the researcher made sure not to comment on or to judge any participant's views, even though he might not have agreed therewith.

This qualitative study design furthermore corresponded well with the researcher's interests and abilities. He has a keen interest in human behaviour, is a careful observer, possesses appropriate communication and people skills and has a well developed writing ability. By following a qualitative study approach, the researcher did spend a substantial amount of time in the field and was often in very close contact with the participants. This gave the researcher the opportunity to observe the participants in their clinical context and his first hand exposure to the collected data did enhance his knowledge of the study material considerably.¹⁰⁰

3.14 Ethical considerations

The researcher submitted his research proposal to the Human Research Ethical Committee of the Faculty of Health of the University of Cape Town for ethical approval. The Committee's approval had been obtained before the study commenced. Before the interviews were performed the researcher had obtained fully informed written consent from the participants after they were thoroughly and truthfully informed about the purpose of the study. The

interviewees' right to privacy was respected by assuring their anonymity and the participants were assured that no physical and emotional harm will be caused during the interviews. The researcher treated the participants with respect and dignity as individual human beings and did not attempt to manipulate them. The interviewees were allowed to withdraw from the interview at any time, as described in the informed consent document.

Each interview was followed by a debriefing session during which the participants were given the opportunity to ask questions or to make comments and to make sure that no harm has occurred. GVI Oncology has according to policy an oncology social worker present at each unit as well as a contracted outside independent counseling service available free of charge for counseling of staff in distress. These services were available for the participants in case the interview caused any distress or if burnout was suspected. Information leaflets regarding burnout and the management thereof were also available for the participants at risk

All recorded interviews as well as interview transcripts were stored on a password protected computer. All recorded interviews were destroyed after the transcription process. Participants were informed that they would get comprehensive feedback with regards to the outcome of the study. All participants will receive written feedback via email, academic sessions and conference meetings. A peer reviewed article will also be available on the findings of the study.

3.15 Conclusion

The researcher has decided to conduct his study on the evaluation of the current practice of oncologists working in a private oncology clinic in South Africa, managing patients with solid tumours whose disease does not respond to anticancer treatment. After considering the different study designs available, the researcher has elected a basic, cross-sectional qualitative approach using in-depth semi-structured interviews with private oncologists to perform his research. The research was performed at the outpatient treating units of the private oncology company, GVI Oncology, and treating oncologists were used as study population. The researcher used a face to face, cross-sectional, semi-structured interview with the aid of a topic guide as data collecting tool and employed the process of coding to organise and manage the collected data. Ethical considerations were taken into account when the study was performed.

The final results, conclusions and recommendations of the study will be distributed amongst the oncologists and clinical staff of the treatment units where the study was performed and an article of the study results will be published in a peer reviewed journal.

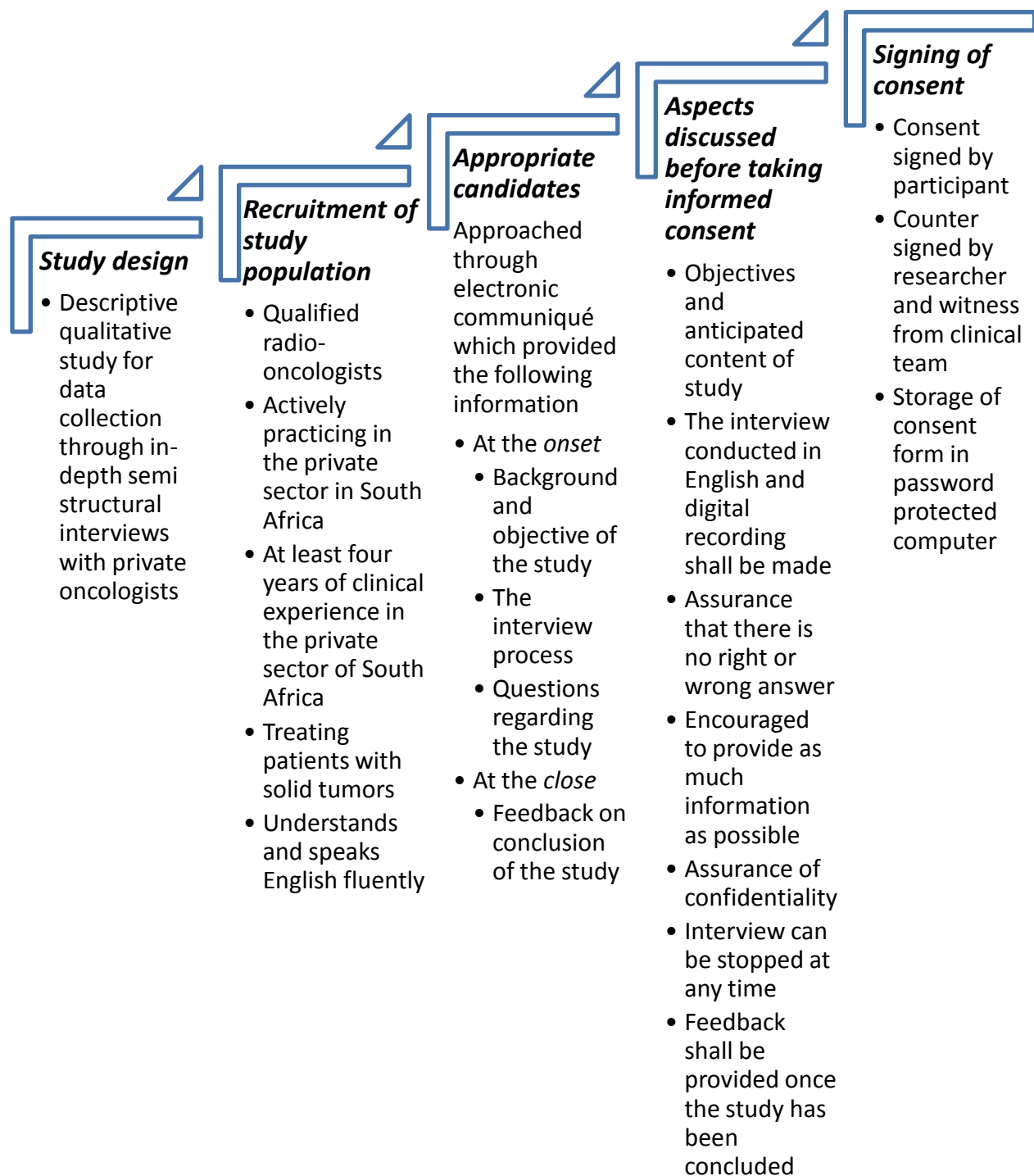


Diagram 1: Study design and consent

CHAPTER 4: Research findings

4.1 Introduction

The researcher conducted a qualitative study which was focused on the current practice of South African oncologists in private oncology units with patients whose disease had become incurable. The researcher employed face to face, cross-sectional, semi-structured interviews with the aid of a topic guide to obtain data from fifteen participating oncologists regarding important aspects of this particular topic. The data gathered by means of these interviews is presented in this chapter through a narrative approach. Themes and sub-categories produced by the process of coding will be described and supported by relevant quotes from the reported interviews. A network display is used to visually present the findings deduced from the data. A summary of the demographic information of the oncologists who participated in the study is given in the paragraph below.

4.2 Demographic data of participants

Fifteen radio-oncologists participated in the study which was performed in five outpatient oncology units situated in the Western Cape Province of South Africa. The participants comprised seven female and eight male oncologists with an average age of 47 years. Each oncologist had a minimum of four years practical experience in the private oncology sector. On average the participants had twelve years experience in the private sector. The participants specialised mainly in solid tumors with experience in melanoma, urogenital, breast, head and neck, thyroid, gastro-intestinal, lungs, gynecological and neurological tumors. Three oncologists consider themselves to be generalists in the field of oncology. On average 45% of the participants' practices consist of patients suffering from metastatic disease.

The interviews were conducted at five Cape Town satellite units of the private oncology company, GVI Oncology. These units include the Rondebosch Unit in Rondebosch, the Vincent Pallotti Unit in Pinelands, the Panorama Unit in Parow, the Cape Gate unit in Brackenfell and the Vergelegen Unit in Somerset West. Each unit has three practicing oncologists who participated in the study. The interviews were held during a seven month period with the first interview performed on 31 July 2012 and the final interview on 27 February 2013. The average

duration of the interviews was approximately 16 minutes with the shortest interview of 9 minutes and the longest interview of 22.10 minutes. The demographic data is displayed in the table and graphs below:

Table 1 – Demographic data

Interview nr	Date of interview	Duration of interview (min)	Age of oncologist	Gender of oncologist	Treatment unit	Years practicing as a private oncologist	Tumour speciality	Percentage of patients with metastatic disease seen in practice
1	2012/07/31	00:21:31	38	Male	Rondebosch	9	Breast, Gastro Intestinal	50-60%
2	2012/08/07	00:12:19	47	Female	Rondebosch	14	Melanoma	50%
3	2012/08/08	00:09:54	44	Female	Rondebosch	4	Urogenital, Breast	30%
4	2012/08/16	00:16:53	41	Male	Vincent Pallotti	7	Urogenital, Gynecology	50%
5	2012/08/21	00:18:45	39	Male	Vincent Pallotti	4	Gastro Intestinal	60%
6	2012/08/31	00:16:30	41	Male	Vincent Pallotti	4	Head and Neck, Neurology	50%
7	2012/09/06	00:09:00	54	Male	Panorama	16	Head and Neck, Neurology, Urogenital	60%
8	2012/09/06	00:10:45	45	Male	Panorama	14	Lungs, Gastro Intestinal, Neurology	60%
9	2012/09/28	00:21:10	52	Female	Panorama	18	Breast	10%
10	2012/10/12	00:10:23	58	Female	Cape Gate	22	Breast, Gastro intestinal, Thyroid, Neurology	50%
11	2012/10/19	00:09:49	48	Female	Cape Gate	20	Head and Neck, Gastro Intestinal, Lungs	60-65%
12	2012/10/31	00:22:10	55	Male	Cape Gate	19	Generalist	50%
13	2012/11/22	00:11:24	41	Female	Vergelegen	5	Generalist	50%
14	2013/01/17	00:09:25	56	Female	Vergelegen	11	Generalist	60%
15	2013/02/27	00:21:03	51	Female	Vergelegen	13	Breast, Gastro Intestinal	30%

Figure 1 – Gender of Oncologists Interviewed

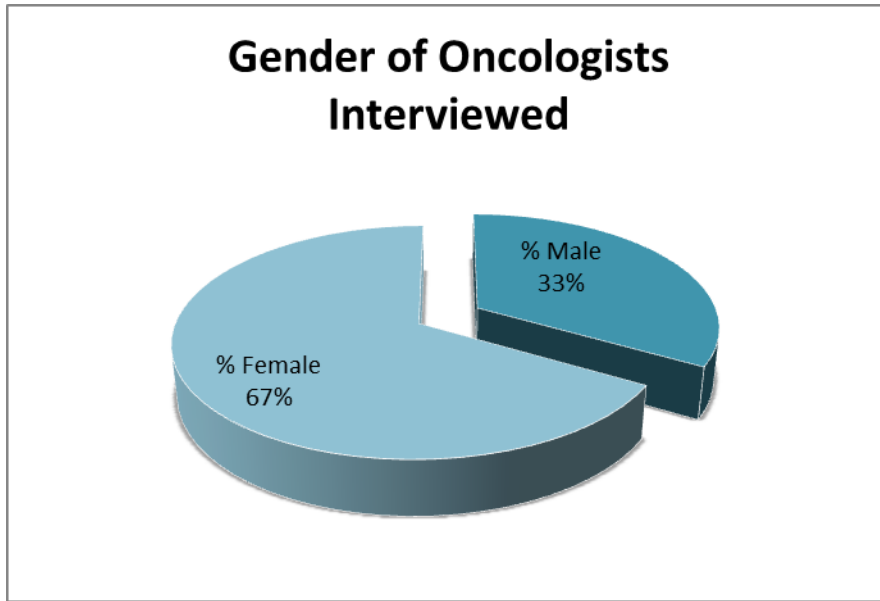
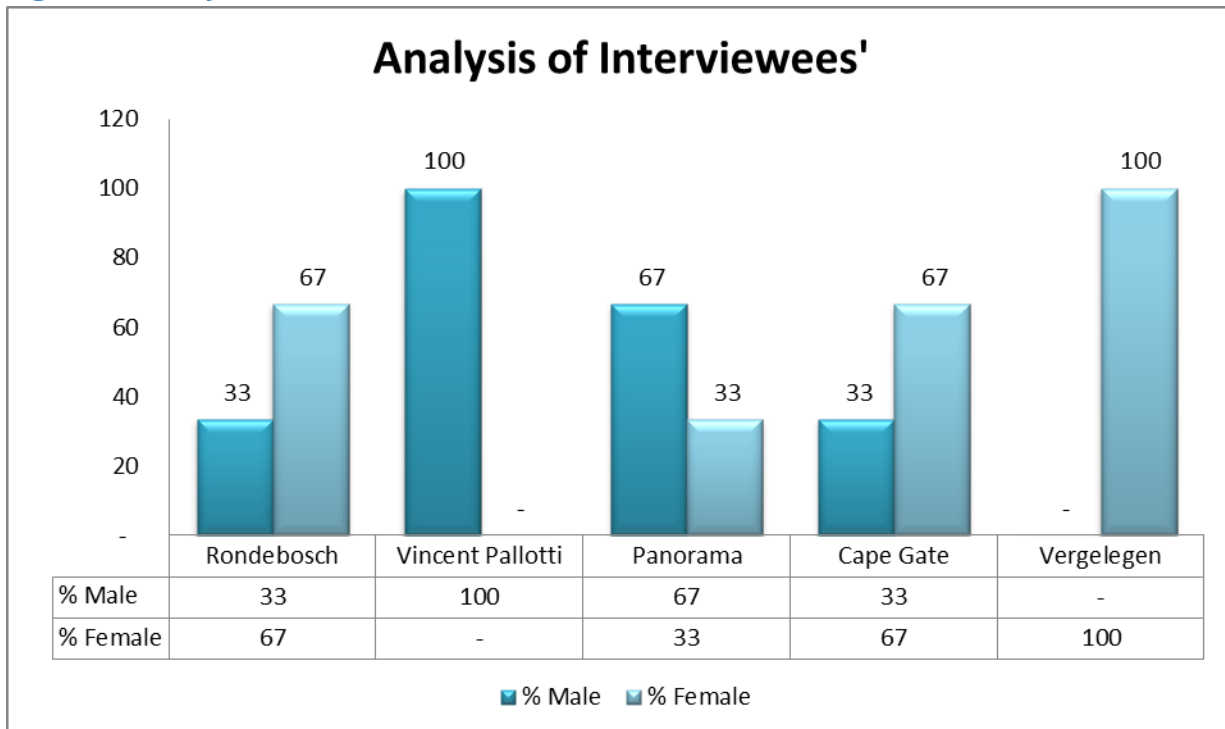


Figure 2 – Analysis of Interviewees'



4.3 Identified themes

Six themes with relevant sub categories have been identified and are summarised and described below.

Table 2 – Themes and Sub-Themes

THEMES AND SUB-THEMES: THEME 1-3		
Theme 1: Oncologists’ experiences regarding the management of patients with advanced disease	Theme 2: The difficult discussion when a patient’s disease has become incurable and when it has to be decided whether anticancer treatment should be stopped	Theme 3: The decision to stop anticancer treatment
1.1 Familiarity of oncologists in dealing with patients with advanced disease	2.1 The approach of the oncologist	3.1 Oncologists’ approach to palliative chemotherapy
1.2 Challenges in managing patients with advanced disease	2.1.1 The importance of being open and honest	3.2 Factors influencing the oncologists’ decision to stop anticancer treatment
1.2.1 Treating young patients with advanced disease	2.1.2 Early notification of patients of their disease status	3.2.1 Disease factors
1.2.2 Treating patients who are in denial	2.1.3 The importance of a relationship based on mutual trust	3.2.2 Patient factors
1.2.3 Treating patients to whom the oncologist became attached to	2.1.4 The importance of realistic hope	3.2.3 Financial factors
1.2.4 Dealing with the patients’ family members	2.2 The contents of the discussion	3.2.4 Influence exerted by the family of the patient

1.2.5 Time constraints associated with the management of patients with advanced disease	2.3 Difficulties experienced by oncologists with the discussion	3.2.5 Influences of working in the private sector
1.3 Rewards associated with managing patients suffering from incurable disease	2.3.1 Loss of hope when the patient is informed that his disease is terminal	3.3 Strategies to work with the patient and his family
1.4 Personal characteristics needed to manage patients with advanced disease	2.3.2 Discrepancy between the patient and family members	
	2.3.3 Oncologist perceived as a failure	
	2.3.4 Dealing with emotions of patients and family members	
	2.3.5 When patients are reluctant to accept their disease status	
	2.3.6 Time constraints associated with the discussion	
	2.3.7 Issues regarding treatment decisions concerning patients fit for treatment	
	2.4 People participating in the discussions	
	2.5 Follow up plans given to patients after the discussions	

THEMES AND SUB-THEMES: THEME 4-6		
Theme 4: Advance directives	Theme 5: Oncologist burnout	Theme 6: The palliative care team approach
4.1 Oncologists' views on advance directives	5.1 The effects of working with advanced disease patients	6.1 The oncologists' understanding of the concept of palliative care
4.2 Timing of the discussion	5.1.1 Emotional effects	6.2 The appropriate time to introduce palliative care
4.3 Difficulties associated with the discussion of advance directives	5.1.2 Physical effects	6.3 Training of oncologists in palliative care
	5.1.3 Effects on daily work	6.5 Shortcomings in the current palliative care services
	5.1.4 Effects on social interactions	6.6 Recommendations to improve palliative care facilities currently available at treatment units
	5.2 Strategies for burnout	6.6.1 Involving the patients' GPs
	5.2.1 Regular breaks	6.6.2 Early referrals to hospices
	5.2.2 Counseling, debriefing and support	6.6.3 Employment of a palliative care physician
	5.2.3 Extra-occupational interests	6.6.4 Providing exclusive palliative care services
	5.2.4 Maintain an emotional distance	6.6.5 Employment and training of medical officers and nurse practitioners

	5.2.5 Delegating work activities	6.6.6 The presence of an oncology social worker/counselor
	5.3 Support at work for burnout	6.6.7 Making use of palliative care guidelines

4.3.1 Theme 1: Oncologists’ experiences regarding the management of patients with advanced disease

This theme explored the oncologists’ experiences on the management of patients whose disease has become incurable. The oncologists shared their feelings and experiences in this regard. The frequency in which they dealt with such patients, the difficulties and advantages associated therewith as well as the personal characteristics necessary to work effectively in this field were all topics that emerged during the interviews.

4.3.1.1 Familiarity of oncologists in dealing with patients with advanced disease

Nine participants indicated that they acquired extensive experience in the management of patients whose disease had become incurable and that it constitutes a major portion of their daily work.

- *“I probably do have a wealth of experience just by virtue of fact that, sooner or later, you know, a great proportion of our patients land up that way.” (4)*
- *“Well, I’ve obviously have dealt with that a lot over the years cause we are with patients from their diagnosis all the way through, through the adjuvant and when they get a recurrence and then go through palliative active therapy and then eventually the difficult conversation of...of changing to best supportive care approach. So I have a lot to do with that.” (8)*
- *“I have a fair amount of experience in this. Most of our patients, well, probably half of our patients are palliative patients and then you always get to the point where you stop treatment and go into a medical palliation only situation.” (13)*

Two oncologists mentioned that possible reasons for the high load of patients with advanced disease in their practices could be due to inadequate palliative care services as well as a lack of proper screening programmes in South Africa.

- *“We do developed quite a lot of experience just by virtue of the fact that there is not always very developed, sort of palliative care in...in our units.” (5)*
- *“The majority of the patients that’s referred to us are advance because the screening programs in South Africa are inadequate and because we don’t have adequate palliative care facilities that’s incorporated in the practice.” (11)*

One oncologist who specialised in breast cancer concurred with the above view and submitted further that adequate screening programmes, as implemented by her team, reduced the number patients with advanced cancer treated in her practice.

- *“When I started about twenty years ago it was a...the majority of my patients and in time spending more than fifty percent of my time managing those patients, but through the advances of breast cancer, we now do genetic profiling, prognostication, we identify the high risk patients better so the appropriate patient gets better adjuvant therapy and the response rate and outcome so much better.....so our unexpected metastatic disease is very, very low, local recurrence is low. I end up now doing less than 10 percent of my work is metastatic, uhm, the majority is adjuvant therapy.” (9)*

4.3.1.2 Challenges in managing patients with advanced disease

Seven oncologists mentioned that treating patients with advanced disease can be a very difficult task. Demanding challenges, such as time constraints, futile treatment efforts and the emotional burden associated therewith are some of the reasons given why this field is not so popular amongst them.

- *“I probably dislike it more than I like it in that it usually means a failure of my discipline.” (3)*
- *“It’s not a field that I particularly like because it’s quite difficult to support the patient...it’s quite a challenge.” (7)*

- *“I’m not averse to the field, I find as I get older I struggle more emotionally with it, I seem to be less able to detach myself from the process.” (11)*
- *“I think it’s quite a challenge, I think number one, it takes quite a bit of time, that as a full time oncologist you often don’t have...So, it’s time consuming and also, I think, emotional challenging.” (15)*

Thirteen oncologists mentioned some of the difficulties associated with the management of patients suffering from advanced disease which included the following:

a) Treating young patients with advanced disease

Seven participants admitted that the management of young patients can be very emotionally demanding. These patients’ will to improve their condition and their determination to fight their disease exert additional pressure on the treating oncologist.

- *“Younger patients tend to be I think, more emotionally demanding, I think because obviously there’s more of a ...(pause)... need to hope that you are going to provide curative therapy...so that sometimes is emotionally more burdensome to some degree.” (1)*
- *“It affects me a lot if the patients are young, you know, you’ve walked a path with them through their disease and, you know, ... (pause)... that’s quite distressing.” (12)*

One oncologist admitted that dealing with older patients are easier as they often are prepared to accept their disease status more readily.

- *“It’s easier for me to manage a palliative patient that’s older than a younger patient with children. So just emotionally also easier, because with older patients often they’re quite comfortable with just having symptoms managed.” (15)*

Three oncologists mentioned that they relate more to younger patients, especially to those who have small children. However, it is difficult to manage such patients with the required professional distance.

- *“I struggle with young...with woman with children. I can’t...cause it’s just because you relate in terms of where you are. I had my children at thirty six and forty two so I find it quite difficult.” (11)*
- *“Younger patients that...that I can identify with who still have small children for example, I find that quite emotional and difficult.” (13)*
- *“I had a young twelve year old girl who died of a glioblastoma, it’s very traumatic, you know. A lot of our staff also, they recognise their own kids who’s almost that age. So that’s very traumatic. I think it hits home. We expect an older person to die; you don’t expect a child to die from a tumor.” (6)*

b) Treating patients who are in denial

Two oncologists commented on the challenges that are associated with patients who do not acknowledge the severity of their disease and, consequently, always insist on more treatment.

- *“Where we also struggle with is in patients who do not kind of reach the level of acceptance that you anticipate. So we sometime struggle with patients who ... (pause)... you know from a denial perspective fail to really ... (pause)... see or acknowledge where the disease is headed or going and that is sometimes quite emotionally burdensome.” (1)*
- *“It’s quite an emotional thing. The patient always want to feel something can be done and you’ve got to be honest and they sometimes lose interest in you.” (7)*

c) Treating patients to whom the oncologist became attached to

Two oncologists described the difficulties they experienced with the management of patients to whom they had become attached and whose disease became incurable. Such difficulties were especially prominent when the patient reminded them of a family member or a close friend.

- *“There are always patients that’s kind of...you...you kind of relate to better than others for whatever reason, their personalities more compatible to yours. They remind you of*

somebody in your family or there's some...something along that way where you...you kind of bond more with them. So obviously there is a sense of sadness when those patients deteriorate.” (2)

- *“The difficulty is with patients that I’ve been caring for, for a long time, usually in the adjuvant setting that then develop metastatic disease. Hmm, and I think about them sometimes at two am. Hmm ... (pause)... and I’m sad. It’s difficult to actually look after them.” (3)*

d) Dealing with the patients’ family members

Three oncologists admitted that dealing with family members of patients suffering from incurable disease can be both emotional and time consuming.

- *“I think being in charge of looking after patients who are dying and their families and in particular their families is emotionally very draining...and from the point of view of emotions and from the point of view of being very time consuming as well in a busy day.” (4)*
- *“Sometimes it doesn’t go well or there is a lot of distress in families and that...that can be quite tough you know.” (5)*

e) Time constraints associated with the management of patients with advanced disease

Four oncologists commented on the time constraints associated with the provision of proper palliative care to patients suffering from advanced disease. The support of family members and added paperwork exacerbated inroads made on their available time.

- *“You also have the sense that you want to try and be there sort of emotionally or just physically be around for family and..and make them feel that you kind of there for them in that process, and I think that’s often difficult cause of the time constraints involved.” (5)*
- *“It’s very time consuming to do proper palliative care.” (6)*

- *“The burden of added paper work and unfortunately palliative patients add more paper work because you end up getting a lot of referrals and motivations.” (15)*

4.3.1.3 Rewards associated with managing patients suffering from incurable disease

Despite all the difficulties and challenges associated with the management of patients with advanced disease, five oncologists commented on rewards associated with this challenging field. Being able to control a patient’s symptoms, interacting with the family and involving them in the patient’s care and receiving the family’s acknowledgment were mentioned as being quite rewarding.

- *“...it’s quite rewarding in a way if...if everyone is well prepared and it’s a process that you feel like you’ve managed well and everyone’s been able to anticipate and everything is in place and everyone kind of on the same page and patient’s kind of well controlled...and generally the families or patients are kind of appreciative of all of that and that’s quite rewarding.” (5)*
- *“I think it’s very rewardingly even if you can just relieve someone’s pain.” (6)*
- *“Yes, it’s a field that I like cause I want to have the patient as comfortable as possible and involved the family to help with the terminal care as well.” (10)*
- *“I enjoy the challenges that it comes with and I enjoy the chances it gives you to interact with the patient and their families.” (4)*

4.3.1.4 Personal characteristics needed to manage patients with advanced disease

Two oncologists commented on the personal characteristics that are needed to effectively work with patients with incurable disease. Inner resilience, compassion, understanding and emotional strength were identified as needed traits.

- *“People who are drawn to specialties like oncology and palliative care usually have the ability to cope on an emotional level.” (1)*
- *“You have to have sort of a inner kind of resilience to be able to work in oncology and... but I think you also have to have a degree of compassion and understanding.” (2)*

4.3.2 Theme 2: The difficult discussion when a patient's disease has become incurable and when it has to be decided whether anticancer treatment should be stopped

Oncologists shared their experiences regarding the difficult but inevitable discussion they have to have with every patient whose disease has become incurable and on the decision whether treatment should be stopped. The oncologists' approach to this discussion, difficulties experienced by both oncologist and patient, people that should be present at the discussion and further management of these patients emerged from the interviews.

4.3.2.1 The approach of the oncologist

Fourteen oncologists commented on their approach towards this theme.

a) The importance of being open and honest

Nine oncologists emphasised the importance of being open and honest with their patients. The situation should be explained in a sensitive and gentle way and in understandable language. Ample time should be made available to allow for a thorough discussion of the patient's needs and adequate opportunity for questions should be given:

- *"So really just simply telling the truth in as gentle way as you can but without leaving the patient muddled." (3)*
- *"I try to be sensitive to where the patients are emotionally and very honest with very basic information and then leave spaces for the patient to ask questions so I would take my cues from the patient in terms of what..how much detail they want." (11)*
- *"I try to be as open as possible to my patients and, you know, when I get to a point where I see, you know, that they're not responding anymore, you know, I'll be open to them and say look, you know, it's no use us carrying on with this kind of treatment and, you know, there is no..no other treatment and therefore, you know we need to look at, you know, your needs." (12)*

b) Early notification of patients of their disease status

Two oncologists mentioned the importance of informing advanced stage cancer patients who are on active treatment at an appropriately early stage that a decision on a change of their

treatment from curative to palliative will be unavoidable. This usually helps to improve the transition from curative intent to symptom palliation and gives the opportunity to discuss the initiation of palliative care services.

- *“I think where it is clear that someone has disease that is metastatic or incurable, you really need to try and incorporate that in your discussion upfront. So, all my new patients, I typically make a clear cut distinction between those that are being treated with curative intent and those that are being treated with palliative intent, and I find that that makes the transition easier.” (1)*
- *“If a patient has an incurable cancer, even if they are on active treatment, I’m very conscious of making them aware of the fact that their cancer is incurable and that at some stage down the line, they will require the input of a palliative care team. You know, lot of patients’ perceptions of the palliative care service is one that is given in the last week or two of life. And so I try to debunk that myth as much as possible by explaining that most of their work is done as an outpatient and most of their patients are managed for long periods of time prior to any terminal event.” (4)*

c) The importance of a relationship based on mutual trust

Four oncologists highlighted the fact that a patient-oncologist relationship based on mutual trust substantially facilitates this discussion. Each patient’s level of education and sophistication should also be taken into account:

- *“It varies from patient to patient because you obviously have to take into account the patient’s uhm.....level of education and ability to appreciate the sophistication or the patient’s sophistication I suppose as a word.” (4)*
- *“It’s much easier if you’ve walk the road with the patient because then you sort of get to know their, you know, their personalities and how you’ll deal with it.” (14)*

d) The importance of realistic hope

Two oncologists referred to the importance that the patient should be given some form of realistic hope that, although curative treatment is going to stop, their care will still continue but that the focus now will fall on quality of life.

- *“...and encourage them that in the time that remains to...to still live life, so it’s not all about taking away hope and the end is now but it’s almost like a transition phase in terms of their life.” (2)*
- *“You need to give them the impression that there is always or not the impression, the understanding that there is always something else to do, we’re just going to do it differently, not giving them active chemo treatment but we can manage pain, we can manage nausea whatever the case may be.” (13)*

4.3.2.2 The content of the discussion

Eleven oncologists commented on the content of this discussion with their patients. Four oncologists usually discuss the different treatment options that are available, emphasising the pros and cons of each specific treatment regime. Patients are made aware of the decrease in efficacy and the increase in toxicity that is associated with each following line of chemotherapy.

- *“I mean, generally how I approach it is, is trying to explain, hmm, sort of, ja, pro’s and con’s to treatment and risks and benefits and try to explain to patients for most treatments you get, sort of, diminishing returns the more different types of treatment you....you give them. They become less likely to have a benefit and more likely to give them side effects.” (5)*
- *“Then you progress through the different treatments and as you progress through the different lines, you also start to communicating the chances of response, say for instance first line metastatic is 50 percent, second line is 30 percent, third line is 10 percent and if they know the chances to get a response is one out of ten.” (9)*

Six oncologists indicated their preference to use the results of special examinations, such as CT-scans and blood tests, to demonstrate to their patients that their disease has progressed. From

there, the conversation progresses naturally to treatment options, prognostication and future care plans and follow ups.

- *“I usually like to have some kind of hard and fast data or pictures or tumor markers or something that I can show them. So it’s nice to have a CT scan that shows progression of disease in the face of the third or fourth line of chemotherapy and..and so you not just talking about, like think it’s not working, it’s kind of some definitive proof that it is not working.” (2)*
- *“I’m talking particularly about survival data and possible symptoms that could happen. I’d be honest and say, you know, we’ve seen your X-ray. As you know you start with advance disease with a poor prognosis and unfortunately you’re not responding to the tumor therapy anymore and then just wait...” (11)*
- *“But I’m just completely opened and honest and tell them, you know, this is what your scan has showed, you know. Unfortunately there are no other chemotherapy lines of treatment, so we, you know, we gonna have to withdraw active treatment but we’ll follow up regularly. Tell them what to look for.” (6)*

Two oncologists emphasised the importance of communicating to their patients the necessity to shift the focus of treatment from prolonging survival to improvement in quality of life when their disease has become incurable.

- *“Hmm, so generally that’s the way I...I convey it. I say, you know, we’ve done as much as we can to keep the cancer under control, now we need to shift our focus to making sure that whatever time is left, is a...uhm...lived in as good or quality as possible.” (4)*
- *“...and then just focusing on the fact that we need to, that we can still be actively involved in their management but more focusing on their quality of life.” (8)*

One oncologist suggested that written information could also be provided to patients and their family members. Such material may also present answers to questions they may have on end of life care.

- *“But I mean there is a lot of information, you know, available, because you often do have, you know, somebody with medical training, who do not understand that part of it. Then I say I’ve got stuff on my computer I can offer you to read, you know, and then I print it out and give it to them. Because that often is a major problem in the end of life scenario.” (12)*

4.3.2.3 Difficulties experienced by oncologists with the discussion

Twelve oncologists commented on the difficulties they experienced when they had discussions with their patients on the incurability of their disease and the possible termination of treatment. The following issues were identified:

a) Loss of hope when the patient is informed that his disease is terminal

Four oncologists mentioned that loss of hope and the inability of patients to accept their disease status are complicating factors that need to be dealt with.

- *“It’s not always a easy conversation to have, uhm, and ja, it’s...if patients are insightful, uhm, it’s obviously an easier conversation to have. But..uh.. ja, lot of them want to live forever, you know, they don’t have the understanding that there’s nothing else out there for them.” (2)*
- *“The news for the patient is catastrophic often. Uhm, and it’s not nice to be the bearer of bad news so that’s probably the main reason why it’s difficult.” (3)*
- *“I think it’s often difficult depending on the patients and their families, I mean if they got a huge amount of hope or...or you can see they’ve got a huge amount of their, sort of moral invested in carrying on with treatment, any treatment, those are...I find those very difficult discussions, you know, where you know that the fact of not giving treatment or withdrawing treatment is going to be a really...you get the feeling it’s going to be quite a devastating blow.” (5)*

b) Discrepancy between the patient and family members

Three oncologists mentioned the challenges that emerge when divergent views are held by the patient and family members regarding the disease that has become incurable. Problems that occur include a difference between the family's requests and the patient's wishes regarding further treatment as well as mixed messages received by family members who do not attend the consultations with the patient.

- *"You may also have a discrepancy in what the patient's wishes are and the family's expectation is." (1)*
- *"I have had one or two patients, I've got one at the moment that I always see alone and that's very difficult because you get mix messages from the family but the patient has never brought anybody with her." (15)*

c) Oncologist perceived as a failure

Two oncologists mentioned that they sometimes experience feelings of failure when their patients' disease does not respond to the treatment they prescribe. They find it difficult accept their inability to fulfill their patients' expectations to be cured.

- *"I think that...(pause)...one when....as doctors we're not used to admitting...a... that nothing can be done from a active treatment point of view and I think even, you know, that..a...we...so we sometimes see it as a failure on our part. A failure to...to live up to the expectations that the patients have, so it's a difficult conversation from that point of view." (4)*
- *"It's quite a challenging field because, you know, patients have expectations of you and they always have a expectation of a doctor that can cure...that you can cure them." (6)*

d) Dealing with emotions of patients and family members

Four oncologists admit that informing patients that their disease has become incurable is usually followed by intense emotions from both patient and family members. Such emotions are difficult to manage.

- *“Oh, I don’t think I’ve...I particularly enjoy that kind of conversation, telling the patient that there’s nothing more active we can do apart from supportive care and what that entails, because it’s a very emotional time for the patient so its...its quite stressful dealing with that.” (8)*
- *“Often the patients are OK but the families are the ones that need assistance.” (12)*
- *“The patients’ reactions to that information make it more or less difficult for oneself.” (13)*

e) When patients are reluctant to accept their disease status

Five oncologists mentioned the difficulties associated with the situation where patients are reluctant to accept that their disease has become incurable. Four oncologists referred to their patients’ loss of hope and their tendency to give up once the decision to stop treatment has been made. The patients usually find it very hard to come to grips with the facts of their disease status.

- *“And the other thing that patients tend to interpret the discussion is giving up hope in some degree that many patients cling on to treatment as some form of hope that we can continue to treat the disease actively.” (1)*
- *“I don’t think the patients have a huge role there, because the facts are there to support stopping treatment as much as they may be not be comfortable with that as a concept.” (2)*
- *“For other patients its quite hard because they actually...they see stopping treatment as...as kind of giving up or...or, you know, it’s kind of...sort of associated with the fact that there is, things are going to get worse very...very quickly.” (5)*

One oncologist mentioned how especially young patients can cling on to the smallest things which may provide some hope regarding the outcome of their treatment.

- *“For a patient, even a one percent chance does make sense. So...not for everybody but for young patients specifically sometimes they would do anything to stay alive longer and sometimes without really insight about the toxicity, they’re so focused on the response and treatment that...that they are dictated by.” (9)*

f) Time constraints associated with the discussion.

Three oncologists mentioned the need for sufficient time to be allocated to allow that a proper discussion could be held with the patient at the stage when his disease is no longer responding to treatment. Time constraints develop when the disease progression is detected unplanned during normal follow up examinations or where patients have difficulty in processing the information given.

- *“It’s very difficult and sometimes it takes two or three conversations before they will realize what you’re saying because we tend to put very nice little words like metastasize and patients have no clue what it is. It’s a difficult one.” (14)*
- *“I think sometimes the unfortunate thing is that it’s often not a planned discussion. So the patient comes for discussion of a scan or something like that and then incidentally you end up with a palliative care discussion where you having to decide that you’re going to stop treatment. So in your day that’s often not scheduled as a longer consult....and to reschedule that kind of appointment I think causes more anxiety, so it’s best to just do that.” (15)*

g) Issues regarding treatment decisions concerning patients fit for treatment

Two oncologists identified issues which complicated the decision to continue treatment. One oncologist mentioned the difficulty associated with continuing treatment on a patient who did not respond to previous chemotherapy regimes.

- *“It gets more difficult in like breast or ovarian cancer where there’s actually quite a lot of options although you know that if they haven’t responded to like two or three in succession, they probably not going to respond to anything else but, you know, you still got another two or three treatments you could theoretically give them.” (5)*

Another oncologist referred to the difficulty experienced when patients refuse continued treatment if the treatment aim is enhancing quality of life and not life extension.

- *“They want to know if it is going to improve their length of life not only their quality of life and then they say no, they don’t want it. So that’s quite a difficult decision.” (6)*

4.3.2.4 People participating in the discussions

Eleven oncologists commented on the people who usually are present with the patient when the news is broken that the patient’s disease has become incurable. Ten oncologists suggested that the patient should be supported on that occasion by at least a close family member or caregiver.

- *“I try to make sure that there is a family member like with my first consultations also. I think it’s extremely important that you actually have someone in the family or close relative, I think it’s actually quite unethical to hand patient information like this on their own.” (11)*
- *“It’s rare that a patient come completely on their own, uhm, and if they do and there is a family member sitting inside, I usually suggest that if they comfortable with it that that person come along to be part of the conversation.” (13)*

One oncologist was of the opinion that the discussion itself should determine who is present or not and that one should just go with the natural flow of it.

- *“For me it’s not really necessary to say who is included, I think the anatomy of that conversation, uhm, will define whether the patient bring in family or not or continuing the conversation or stop the conversation or start crying and you call on to the social worker for that, or start crying and you just stop the conversation because obvious is more than what they can deal with.” (9)*

Seven oncologists mentioned the importance of involving a social worker during the conversation to support the patient and to ensure that the patient fully understands the contents of the conversation

- *“The social worker is going to be part of the meeting, because sometimes, you know, you get carried away in your medical jargon and terminology and the patient might not understand, so she actually stops you and said but what does that mean.” (6)*

On the other hand, four oncologists were of the opinion that the social worker should only be involved after the conversation if it is deemed necessary or during the conversation if it is specifically requested.

- *“Occasionally the oncology social worker is called in for that conversation, but that’s quite seldom that it happens at the same time, they would usually see the oncology social worker afterwards.” (8)*
- *“Very occasionally I’ll call in one of the sisters or social worker to join the consult but I seldom would initiate that kind of conversation with a sort of third party if it’s not related to the family, uhm, in the room.” (2)*

4.3.2.5 Follow up plans given to patients after the discussions

Five oncologists have commented on their follow up plans for their patients after the patients had the conversation during which they were informed that their disease had become incurable. Although the anticancer treatment has stopped, their care of the patient will still continue. The oncologists may withdraw to a certain degree and may not be the sole provider of palliative care. However, they will still see the patients on a regular basis but the aim of treatment will be symptom management.

- *“I still arrange to see patients for follow up, uhm, on a monthly basis and usually leave a open door policy so that they never feel that we’ve discharge them from my care but they have the opportunity to give us a ring and a shout whenever they need to.” (1)*
- *“You will still remain as their carer and you now need to shift your focus away from treating the cancer to treating the patient and to treat the symptoms of the patient.” (2)*

- *“I think we should still be involved although we don’t need to be the sole provider of the palliative care.” (8)*
- *“I’m on the sides, I’ll draw in the GP, I’ll get a nursing carer at home, I’ll get hospice, hmm, and then, in a way, hand over (pause) the main responsibility.” (9)*

4.3.3 Theme 3: The decision to stop anticancer treatment

The oncologists’ approach to palliative chemotherapy, the factors that influenced the oncologists’ decision to stop anticancer treatment in patients whose disease has become incurable as well as strategies to deal with these influences emerged from the interviews.

4.3.3.1 Oncologists’ approach to palliative chemotherapy

Four oncologists commented on their approach on giving palliative chemotherapy to patients with advanced disease. Two oncologists admitted that, as they gained more experience, they became more conservative regarding palliative chemotherapy. Their aim would rather be more on symptom control and enhancement of quality of life than on cytotoxic chemotherapy.

- *“As I’m getting older, I tend to be more, uhm, conservative and I would like to stop earlier because I believe the toxicity versus quality of life balance is really important and sometimes no treatment is also a good management.” (9)*
- *“Having been in oncology so long, you know, I’ve gone past the where you try and cure everybody and you know, try and give everybody as much as possible and I actually was thinking about it yesterday, you know, how my mindset has actually changed through the years and how I’ve become much more, uhm, I don’t know if it’s realistic but more less active in, you know, in treating patients.” (12)*

Two oncologists expressed themselves strongly against continuation of chemotherapy if it is not appropriate or indicated by international guidelines

- *“Obviously you follow international treatment guidelines, you don’t...you can’t thumb suck what you want to offer patients so if you fail the second line therapy and there is no third line therapy then you don’t offer patients treatment.” (11)*

- *“I don’t feel comfortable offering a further line of chemo if I thought that it’s not appropriate. So, uhm, it’s not going to be easy to twist my arm, I’m fairly conservative. So, and I think I’m known in the community to be the conservative one (laughing).” (15)*

4.3.3.2 Factors influencing the oncologists’ decision to stop anticancer treatment

The following factors were identified as having an influence on the oncologist’s decision to stop anticancer treatment.

a) Disease factors

Eleven oncologists stated that a patient’s disease which becomes non-responsive to treatment is a very important indicator that chemotherapy should be terminated.

- *“I think the first factor would be lack of response, so, if the patient is no longer responding to the treatment that would be factor number one.” (1)*
- *“Whether to stop treatment or not is whether it's working or not. If it’s not working then there’s no point in continuing.” (4)*

One oncologist emphasised the importance of being aware if the patient responded to his first line of chemotherapy as this might improve his chances for further treatment response.

- *“I think my approach to that to decide first of all if the patient is treatable, is it a responder or non-responder because that is the crossroad in my mind. A non responder, and there are many trials from the British Columbia group showing that if you fail first line your chances or overall survival is about 12-18 months while if you’re a responder, some of those live for 10 years.” (9)*

Another oncologist pointed out that cancer type, prognosis of the patient as well as treatment options available for that specific cancer should also be considered when deciding on the continuation of chemotherapy.

- *“It’s what cancer they have and what the sort of prognosis for that is and you know, what the different treatment options for that are.” (5)*

b) Patient factors

Seven oncologists admitted that patient tolerance to treatment is an important indicator of whether treatment should be stopped or continued. The patient's ability to tolerate the toxic side effects associated with treatment is an important factor.

- *"Patient tolerability, uhm, so if it's quite clearly a regimen that is not well tolerated that would also be the indication to stop." (1)*
- *"Tolerance, so if there are quality of life issues and the patient is having severe toxicities that can't be manage." (3)*

Seven oncologists pointed out that the patient's preference whether treatment should be stopped or continued must be considered and respected.

- *"Well, the most paramount factor is the patient's choice." (4)*
- *"You know lot of the patients make their own decision and it's just for us to reinforce and to say that it is acceptable." (6)*

The patient's performance status should also be taken into consideration when a patient is on treatment. It should be determined if the patient's physical condition is well enough to tolerate anticancer treatment. This was pointed out by six oncologists.

- *"I think it's just general health of the patient, if they are still in a good physical condition." (10)*
- *"I think for me the most important thing is performance status often. If you're performance status isn't good then I don't even talk chemotherapy." (15)*

One oncologist mentioned that a sub-deterioration in a patient's condition due to an acute event unrelated to his cancer could also influence the decision to continue treatment.

- *"Other issues would be sub-deterioration in patients' conditions. Sometimes they can present with something acute that may be unrelated to the cancer but precludes*

continuing with their therapy...and I'll use the example of a myocardial infarction or pulmonary embolism etcetera." (1)

c) Financial factors

Six oncologists mentioned that insufficient funding for treatment can also influence their treatment decisions. Declining of requests by medical aid schemes for the funding of certain treatment options available for patients is regarded as a severe problem in the private sector. Conveying this news to the patient can also be quite taxing for the oncologist.

- *"I think the (pause) to some extent in the private sector, the decision to stop may be financial, so I think that will be the.... the key indication is to where that becomes relevant uhm is that the patients may not be able to afford it, or their medical aid may decline treatment." (1)*
- *"Sometimes I have got to tell them that the medical aids won't fund anything, that's maybe the worse conversation, tell them there is something available but there is no funds for it." (7)*

d) Influence exerted by the family of the patient

Five oncologists admitted that the family members of patients can have a great influence on both the patient and the oncologists when a decision needs to be taken regarding further treatment options. Some patients are influenced especially by their siblings who can make the decision a difficult one for the treating oncologist.

- *"I think that, you know, one can come under a lot of pressure from family to continue with treatment even if you believe it to be futile." (4)*
- *"It's the siblings, the kids or the brothers and sisters that want different goals and want to influence the patient and ultimately, you know, it's the patient's will, you must think what is best for the patient, that's the ultimate goal, but in real terms it's quite difficult, you know." (6)*

Three oncologists pointed out that more sophisticated patients and their family members can sometimes cause pressure by confronting them with information gathered from the media or overseas sources regarding advanced or new treatment options.

- *“Generally the patients in the private sector are more sophisticated, their families have access to more data and so there’s...there’s...one has to (pause) one spends a lot more time debunking myths and...and...and explaining that even though the newspapers and magazines may say something is a miracle cure, it may (a) either not be appropriate or (b) not available.” (4)*
- *“Well, they often do put pressure on you, you know. They’ve got information from internet, you know, which they bring and they say, you know, but what this and what that.” (12)*
- *“I think there is pressure and often pressure from overseas children with new information and new drugs and things that are available.” (15)*

Four oncologists admitted that often the family members together with the patient will put a great deal of pressure on the oncologist to continue treatment even if the patient is not fit enough or the outcome would be futile.

- *“There have been times where I’ve wanted to probably bail out, rather, because my judgement of their quality of life is that it’s poor and they’re not really benefiting despite the fact that they might have stable disease radiologically, uhm, and then there has been pressure from the patient as well as the family and then I have continued.” (13)*
- *“Patients and families tends to be..rather wants to push on, wants to continue on. I very often had to convince people not to have treatment as suppose to the other way around because they are always looking for something more, something extra.” (10)*

e) Influences of working in the private sector

Ten oncologists admitted that the private sector does offer more treatment options to choose from when compared to the government sector, especially in the palliative setup. This can elicit

pressure on the oncologist as the affluent patient is provided with the opportunity to continue with chemotherapy. In the government sector treatment often is stopped due to limited resources.

- *“I think patients perceive the private funding having...sort of being endless. You know, there must be something out there that we can still try.” (2)*
- *“Yes, uhm, having work in the state previously, one would definitely stop with active treatment sooner and possibly after given radically treatment one may not actively palliate with..with chemotherapy or radiotherapy because the resources aren’t available. Uhm, in private the resources are more available so yes, certainly there is more active treatment that is given to patients.” (3)*
- *“I think that there is more lines of treatment available and those lines become less and less likely to work as you go along, but because you have them at your disposal, it’s sometimes very easy to offer a patient another line of treatment rather than having a difficult conversation with them about whether their treatment is futile or not.” (4)*
- *“I think you have more options in private, so, I think they would stop a lot earlier in government hospitals because there are not so many options and they favor the patient where you thrive for cure, when stage four palliative, you try to buy time.” (9)*

Two oncologists mentioned that although all these treatment options are available in the private sector, the availability thereof should not influence the oncologist’s treatment decision.

- *“I don’t think it has a huge impact. I think it’s more just on what’s appropriate for the patients.” (5)*
- *“We’re in a very strict managed care environment, so, I mean, very few doctors can offer patients whatever they want, I mean it doesn’t exist.” (11)*

4.3.3.3 Strategies to work with the patient and his family

Five oncologists mentioned that a good, honest relationship with the patient and effective communication regarding the decision to stop treatment is vital to overcome pressure from the

patient or his family that treatment be continued. Managing the family effectively is also just as important as managing the patient.

- *“I do my best not to....not to be influenced by the family...but to explain to them that, just like the doctor mustn't feel like they're failing the patient if the treatment is not working, the family shouldn't feel like they're failing the patient because the treatment isn't working either. Uhm, and so managing the family in these situations is as important as managing the patients.” (4)*
- *“I think when you're honest and you build a trust relationship from day one and the family and the patient understand that I am here for you. I always say to my patients in the first consultation, remember, I am in your team and every face you see in this unit also aims to help you with this whole journey through your cancer treatment, so then, then there is a trust relationship and then..then it's much easier to communicate openly.” (11)*
- *“It's rare that, you know, if you had the conversation with them properly, that they....that they insist on more treatment.” (13)*

One oncologist emphasised the importance of not wasting limited resources on futile treatment options.

- *“We as doctors have a responsibility not only to our patients, but also to society, not to spend limited resources on futile treatments....and the most important thing in that scenario is to make the patients aware of the fact that just because there is a drug out there, it doesn't mean that that drug is going to work, and even if that drug works, it will not cure their cancer. It may prolong their current situation but not at any great benefit to them.” (4)*

Two oncologists mentioned that in some exceptional cases flexibility may need to be applied when considering continued treatment.

- *“But you know there's also exceptions, you know. Some people wants to see their daughter getting married in September and then, you know, even if there is...you know,*

you have to just try and push them to keep them alive until then, you know, cause that's...that's what they living for, they are holding out for that.” (6)

- *“There have been times where I’ve wanted to probable bail out, rather, because my judgement of their quality of life is that it’s poor and their not really benefiting despite the fact that they might have stable disease radiologically....and then there has been pressure from the patient as well as the family and then I have continued. I’m thinking of one case in particular. But for him his quality of life was acceptable. So, you know, sometimes you also need to allow that flexibility in terms of the judgement in quality of life. It’s not only my impression but theirs that counts as well.” (13)*

4.3.4 Theme 4: Advance directives

The oncologists’ views on the development and implementation of advance directives as well as the timing of a discussion on this subject with their patients and any difficulties experienced by themselves and by the patients in this regard emerged from the interviews.

4.3.4.1 Oncologists’ views on advance directives

Seven oncologists admitted that discussing advance directives with their patients is usually neglected and is not routinely done in their practices. In most cases the oncologists are of the opinion that advance directives imply that, on further deterioration of a patient with advanced disease, active resuscitation will not be appropriate.

- *“Neglected, it’s not something that we would routinely discuss.” (3)*
- *“I think that uhm, we as oncologists are often guilty of just presuming that it is implied as far as advance directives goes and never actually having the....the actual conversation about whether a patient should be resuscitated or not in a futile situation.” (4)*
- *“I don’t particularly discuss it with patients. I mean, I don’t ask them whether they have a living will. I don’t specifically stipulate that if you were to be in a situation where you needed resuscitation that we wouldn’t, I suppose I assume that it implied.” (13)*

Four oncologists considered the discussion of advance directives with their patients as positive. In their view such a discussion will serve to clarify uncertainties which will, eventually, decrease

pressure on the oncologists when decisions need to be taken on whether a patient needs to be actively resuscitated or not.

- *“It’s something I try to encourage because I...I always say to patients it’s better to plan for the path ahead and know what their wishes are. So, you know, if it’s quite clear that someone has...is reaching or reached the terminal phase of their illness, it’s a...it’s a topic that we try and broach fairly early because it’s good to know what the wishes of the patient is so that we’re not caught out in a sort of urgent scenario.” (1)*
- *“The problem becomes when you...when someone maybe who was previously doing relatively well from their cancer and then suddenly has a deterioration and you’re not sure whether you can reverse it or not, or they get a bad pneumonia out the blue and you...and you got no idea how they really felt about...about what they would want done if they needed to go to ICU or...and that...so.” (5)*

Seven oncologists commented that the issue of advance directives is usually broached by the patient and his family. Hence they will only participate in such a discussion when the subject is raised by the patient.

- *“It does come up but usually at the initiative of the family or the patient.” (3)*
- *“I think...from my point of view, the patient will drive it. They sometimes will say, uh, please, don’t keep me alive and I commonly will answer, I know that about you. You know, it’s almost like a non written...agreement if you understand that patient, where obvious the one pushing for treatment is never gonna get to that point, they will do anything to stay alive, so it comes as part of the personality I think.” (9)*
- *“We’ve had one or two patients who have directed us that they have a living will but normally no, I haven’t discussed it. I would discuss it if the patient brought it up.” (15)*

Three oncologists admitted that they will not resuscitate a patient who suffers from advanced disease even if advance directives were not discussed with the patient. Still, they will manage treatable causes of distress.

- *“I practice that even if patients don’t sign it. Uhm, you know, I think there comes a point where patients has got advance disease and they’re beyond salvage. One could be supportive in therapy, care in the ward or whatever but (pause) ja, I think.....just in terms of out of respect for the person you don’t want to go on treating or resuscitate somebody who clearly hasn’t got a life that’s worth living.” (2)*
- *“Some patients will tell me that they do have a living will, uhm, but I treat them the same as if they had one or not. I never gonna use advance...I never gonna put somebody on life support, on a ventilator, uhm, just to keep them alive if there’s no hope of them, uhm, responding to any treatment. I will use...I will put them in ICU, I will support them, put them on a ventilator if it is a chemotherapy related complication, uhm, that they...that they can get through and then have...have further survival, uhm, but not if its due to their disease and if there is no proper responding.” (8)*

4.3.4.2 Timing of the discussion

Four oncologists admitted that their discussions with their patients regarding advance directives will usually take place when the patients’ conditions have deteriorated to such an extent that possible arrests are anticipated.

- *“It’s not something that I usually deal with unless the patient has had an acute worsening and sort of comes into the ward and it’s anticipated in fact that they may arrest, then certainly I would discuss it...but otherwise sort of, until we get to that stage, not really.” (3)*
- *“I don’t bring it up as a matter of routine unless there appears to be a clinical scenario and the...and the patient’s family are requesting,or look like they may request for the patient to be resuscitated.” (4)*

Three oncologists mentioned that they usually have this discussion when their patients’ diseases become resistant to treatment.

- *“Well mostly if it is metastatic and you see it’s not responding.” (7)*

- *“When they have advance metastatic disease, not responding, I would say after second line of chemotherapy. Maybe it is too late but that’s usually when I...when I start discussing it with the patients.” (10)*

Two oncologists suggested that the discussion be had in the earlier phases of a patient’s disease. This will provide the opportunity to discuss future management plans, should the patient’s condition acutely deteriorates and, for instance, requires measures such as IV hydration and nasogastric feeding.

- *“I think we probably should do it more earlier, you know, if it gets to the point where there’s, you know, those kind of things, particular with regards sort of feeding or intravenous fluids, if they have, can say that if there’s no good prospect of recovery, I don’t want to be put on a drip or be fed nasogastrically then, that would probably you know, help a bit.” (5)*

4.3.4.3 Difficulties associated with the discussion of advance directives

Two oncologists mentioned that time constraints present problems with the discussion of advance directives. Due to acute deterioration of a patient’s condition limited or no time is often available for such a discussion.

- *“Most time you don’t have the time or we don’t catch it in time so patients deteriorate really quickly. But, uhm, it’s important to know if someone, ah, you know, needs to be resuscitated, if they want to be resuscitated, especially in the private hospitals because everyone is for resuscitation.” (6)*
- *“But it’s once again a time thing, there’s so many other things to discuss that you actually tend not to get around to that.” (15)*

One oncologist held the view that the readiness of patients for this discussion may also be a complicating factor.

- *“Not everyone is necessarily ready...uhm...I’d say very few percentage of our patients would volunteer that information.” (1)*

4.3.5 Theme 5: Oncologist burnout

The exploration of this theme investigated the presence of burnout amongst the participating oncologists. The emotional and physical effects of working with patients with advanced disease, strategies to overcome burnout as well as support systems available at their units emerged from the interviews.

4.3.5.1 The effects of working with advanced disease patients

Oncologists were requested to discuss the effects that working with patients whose disease has become incurable have on them and how it influence their work and daily living.

a) Emotional effects

Nine oncologists admitted that working with patients with advanced disease can be extremely emotionally draining at times.

- *“Emotionally it’s very draining managing patients with..a...with incurable disease.” (4)*
- *“It can be sort of a emotionally, it can be emotionally pretty tough, you know, when you’ve got a day when you got to have like three conversations with, with families of patients who are sort of terminally ill in the ward, that’s just draining.” (5)*
- *“It has got an emotional impact. I don’t have, let’s say sleepless nights, I’m not depressed or anxious about it, but I mean, I think about the family, I think about the patient, you develop a relationship with them, it’s actually quite sad when someone dies.”*
- *“I think we are in a state of, let’s say post traumatic stress but, uhm, in a way incurable because there are just so many traumatic events that the one sort of feeds from the other. So I think the doctors may be in a bad way and the staff also.” (7)*

b) Physical effects

Four oncologists commented on the physical effects that working with patients with advanced disease have on them. Fatigue was mentioned as the most common physical effect.

- *“The physical aspects of that is that, you know, you certainly, you know, I think, fatigue.” (1)*
- *“That sort of emotional, uhm, sort of burden that you carry has an impact physically in terms of just fatigue.” (2)*

c) Effects on daily work

Two oncologists mentioned that the combined emotional and physical effects of working with patients with advanced disease impact negatively on their work performance.

- *“There’s just some days where you don’t always have like the...the sort of emotional or the physical reserve, you know, it’s like the end of a long day and it’s kind of six’o clock and you want to get home and it’s like do I...do I go and do like one more turn in the ward and see how that patient is doing because it would maybe mean a lot to the family but then you kind think well gees, I’ve got to get...maybe I need to go and see my own family today (sigh & laughing). So it’s quite...it’s like...so that’s sometimes quite hard.” (5)*
- *“I spoke to a...somebody, his dad was a patient here with one of my colleagues and....he said that what was worrying him was he’d looked at the doctor and he could see that this man was so tired and so out of energy and he was worried about the impact that this very fatigued or depressed doctor is going to have on the outcome of his father’s disease and, uhm, ja, I must admit I’m sure patients saw me in that phase of my life as well where you cannot say sorry, I feel extremely fatigue and depressed....you don’t share that with them, I just withdraw.” (9)*

d) Effects on social interactions

Two oncologists admitted that the emotional and physical effects of working with patients with advanced disease make them irritable and frustrated. This often leads to harsh and unnecessary outbursts against family members, staff and patients.

- *“I think the most common thing for me is that I become very ,very irritable and...just want to jump of the bridge (laughing) not literately, so, uhm, I can see it in my staff when one becomes more, you know, irritable, frustrated.” (14)*
- *“I find that the place where you’re going to do it the easiest is you end up shouting at the kids. So, uhm, and they’re old enough now that they actually say, jeez you know, you actually need a holiday or you need a break. But sometimes you end up also getting unnecessary irritated with patients and then you realize that this patient is getting to you because you’re emotionally not well.” (15)*

4.3.5.2 Strategies for burnout

Fifteen oncologists commented on their approach to prevent and counteract burnout caused by working with patients with advanced disease. The following recommendations were made:

a) Regular breaks

Seven oncologists mentioned that it is crucial to get away from the stressors of work to recharge. Hence, regular breaks and frequent holidays are essential, although not always possible. Taking one afternoon off per working week and the sharing of afterhours calls are also regarded as positive strategies. This could be possible in a group practice.

- *“I think also the fact that being in a big practice, you have the opportunity to be off, so, you know, you’re not always on call, and when you’re off your off! You don’t come in and work over weekends, you know, as far as possible. Uhm, and...to have...the other thing is to have regular breaks and that’s not always possible just in terms of cross cover and so on.” (2)*
- *“I try and spend as much time away from work and when I am away from work I try and disengage as much as possible and I take lots of holidays and I break my work week up with a round of golf on a Thursday afternoon.” (4)*
- *“I think you know, you need to have time off, that’s one thing. So being in a group practice, not a solo practitioner. You can’t be on call 24/7, that’s the one thing. I tried that for a year and had my gall bladder taken out.” (6)*

- *“But, I think that for me, I need to take regular holidays. So I actually take four holidays a year coinciding with the school holidays....I also find that since I’ve forced myself to take an afternoon of every week and not use that afternoon for catching up with admin, that’s also good.” (15)*

b) Counseling, debriefing and support

Six oncologists emphasised the importance of the availability of a good support system such as family members, counselors or even the practice social worker for debriefing and support. They also experienced debriefing amongst fellow oncologists as a good source of support.

- *“We have a social worker who if you really need to discuss issues with to share the load at another avenue.” (1)*
- *“Just sort of getting my own counseling and sort of talking about it. Particularly at the moment I’m having a look at the balance that I have with patients between being caring and involved but not too emotionally involved, so it’s sort of work that is going on the moment and sort of defining that balance a bit better.” (2)*
- *“And then giving yourself like space to talk to difficult things to colleagues, I mean it helps if you got people at work that you can sort of debrief about stuff. I think it would...its quite hard if you don’t have those.” (5)*
- *“I have a good stable marriage which I think makes a big difference and I’m allowed to talk about my work at home. The only thing that I’m not allowed to do is to talk about death and dying at social functions, so I get...he knocks on my knees under the table.” (11)*

c) Extra-occupational interests

Nine oncologists mentioned that outdoor activities and hobbies such as exercising, travelling, gardening, sports and spending time with the family are good measures to prevent burnout.

- *“I think if you have got a hobby it’s excellent or a sport that is all excellent ways to do that.” (7)*
- *“I...tend to de-stress by physical exercise, I gym quite a bit, I go for hikes, I’ve been to Everest this year and, you know, Kilimanjaro and various...various other hikes. I like to cycle regular, so that exercise and getting away from work and doing that, also spending time with the kids, uhm, family, that helps me to de-stress.” (8)*
- *“I try to get away over weekends and put my hands in the soil and dig in the garden or whatever and obviously drink too much wine.” (14)*

d) Maintain an emotional distance

Three oncologists referred to the importance of distancing themselves emotionally from their patients to prevent burnout.

- *“If I meet a patient who is incurable from the beginning, uhm, I tend to be much more distant from them so there is no pre-existing relationship, so it’s really about being compassionate and providing for their needs but I don’t invest emotionally and am not really affected as much.” (3)*
- *“...you can, sort of a personal point of view...you can keep it a professional, kind of distance to it” (5)*

e) Delegating work activities

One oncologist pointed out that the sharing of the workload with other staff members also contributes towards the prevention of burnout

- *“Sometimes you need to try and delegate tasks, you know. Maybe there’s some things that I don’t have to be doing, you know, whether it’s a phone call that like a nurse practitioner can make or a motivational letter someone else can write or an email that your social worker can send that doesn’t have to be you, you know.” (5)*

4.3.5.3 Support at work for burnout

The oncologists were requested to comment on the availability of support present at their treatment units for debriefing to alleviate burnout. Eight oncologists admitted that no services of this nature are available.

- *“No, no, I think the psychiatrists are also burning out, so no, no support.” (7)*
- *“Nothing, it’s actually quite pathetic, I mean the amount of care we provide the patients and then who cares for the care takers is like my slogan always.” (11)*
- *“Woo, I think that, ja, unfortunately it is something that I don’t think is well managed from a doctor’s perspective. I think that if we look at counselors, they been regularly debriefed or so on, and on an oncology point of view we actually don’t have that.” (15)*

Five oncologists mentioned that debriefing in the treatment units mostly occurs amongst themselves.

- *“My colleagues, they’re very supportive. The partners I work with here in my unit specifically in my unit, I talk to them. I don’t see a psychologist, psychiatrist, counselor...” (10)*
- *“Yes, I think so, we are fortunate that there are three of us, three oncologists. So we sort of understand, I think, between us what is going on and we know our private lives as well so we know what is going on in our lives...and that’s good support.” (14)*

Two oncologists stated that the only support provided by the institution they are working for to alleviate burnout is the granting of leave.

- *“There is nothing provided for the doctors for burnout except leave.” (8)*
- *“I think there is a lack of that, you know, we as the oncologists, you know, have lots of leave, you know. So occasionally when you get to the point where you know I just can’t cope, you take leave.” (12)*

Two oncologists described how time constraints and overloaded working schedules prevent any participation in whatever support is provided to lessen burnout.

- *“I think the staff has debriefing sessions....uhm, but for the doctors there’s....we’re probably invited to those sessions but nobody goes, we’re all too busy.” (8)*
- *“I remember many days where I was ill, fever, diarrhoea, whatever and you cannot dare to phone in and say you’re not coming to the rooms because everybody is booked and the patients are waiting for a consultation for two or three weeks or whatever and to...to..cause all the chaos at..at the rooms due to the fact that you are not well so you rather just come you know. I can’t imagine that I would...I end up in hospital and I was literally admitted from my rooms to the hospital (laughing) because there is just no..there’s no scope for things like that. Ja, there’s not a lot of support there.” (9)*

4.3.6 Theme 6: The palliative care team approach

This theme investigated the palliative care team approach implemented at the treatment units of the participating oncologists. The oncologists’ general understanding of palliative care, the timing of palliative care referrals as well as training received for palliative care emerged from the interviews. The current palliative care setup at their units and recommendations to improve these palliative care services were also examined.

4.3.6.1 The oncologists’ understanding of the concept of palliative care

All fifteen participants were asked to give their interpretation of the concept of palliative care. Only one oncologist mentioned that palliative care entails a holistic approach to patient care incorporating symptom control, psychosocial and spiritual support together with ongoing management of the patient’s disease

- *“...it’s a model of providing care for patients to effectively look after them not only from a physical perspective but also incorporate aspects of psychosocial care, looking at issues of spiritual care, and incorporate all of that in ongoing management of their disease, uhm, focusing on aspects of symptom control, quality of life but also being fairly holistic and encompassing of other aspects related to their disease process.” (1)*

Four oncologists held the view that palliative care involves symptom management by means of medical treatment, radiotherapy and chemotherapy as well as psychosocial support.

- *“My understanding of palliative care is the treatment of patients who have incurable disease, uhm, concentrating mainly on the management of the symptoms related to the disease as well as the patient’s psychosocial well being. I think that probably covers it.” (4)*
- *“Oh, it’s quite a broad definition. It’s probably all encompassing management of a patient, holistic management, looking at caring for the patient psychological as well as symptomatic management, uhm, knowing that you are not offering treatment to prolong survival but rather to improve quality....But that palliative care can take the form of methods including chemotherapy and radiotherapy but knowing that the patient has to be aware that the intent of treatment is not for cure or for improved survival, it is for improvement in symptoms .” (15)*

According to six oncologists palliative care consists mainly of symptom management focused on quality of life and not cure.

- *“Palliative care for me is essentially symptom control...you know, pain control, hypercalcaemia control, syringe drivers, those sorts of things, but to improve quality of life and symptom control.” (6)*
- *“To make the patient as comfortable as possible, as pain free as possible and to optimise quality of life in the terminal phase of the disease.” (10)*
- *“Symptom relief, uhm, is probably the most important part of the palliative...and, you know, making comfortable in a situation where you can’t really offer any other things of helping the patients so comfort and pain relief, you know, oxygen for shortness of breath, symptom management.” (12)*

One oncologist believes that palliative care is the ability of the treating doctor to determine what is important for the patients when they are receiving treatment.

- *“I think it’s the art of medicine. I think that is really where there’s a difference between doctors, in being a good doctor, in being a wise doctor specifically that to understand for some people prayer is a medicine, for some people a drip is medicine, for some people*

touch and attention and time. So, ja, palliative care is, I don't see it only as part of the cancer, it's like diabetes, a management of a patient with a chronic disease.” (9)

4.3.6.2 The appropriate time to introduce palliative care

Ten oncologists commented on the appropriate time to introduce palliative care. Eight oncologists suggested that palliative care should be introduced fairly early during the patient's disease process to make the transition from curative to palliative care as smooth as possible. The introduction of palliative care should coexist with active anticancer therapy to ensure the continuum of care.

- *“I think introducing the concept early on is key, uhm, once again so that the transition is a fairly easy one. Uhm so I think palliative care, certainly for patients with disease where we are not offering cure is something that needs to start from the...from the word go.” (1)*
- *“I think, palliative care can to some extent run in conjunction with active management, it's not one or the other.” (2)*
- *“I think you start palliative care from day one when you actually inform the patient of their diagnosis and definitely when they've got metastatic disease so symptom care goes right through the continuum of care.” (11)*
- *“It is a continuum, so it's not something that starts once you've stop active treatment; it starts earlier on...and symptom management plays an important part right from the start as well as the psychosocial. I think it makes the end phase, uhm, easier.” (13)*

Two oncologists felt, however, that palliative care should be introduced only when a patient does not respond to active treatment anymore and has moved into the preterminal phase of his disease.

- *“If I say this patient is now palliative I would say no active chemotherapy for sure. The patient is not able to live a normal life anymore due to the disease, uhm, and that you can foresee that the survival of that patient is, say whatever you think, 3 months, 6 months or whatever, so I can start to see the end of the line. That is where I think I'd change gears into thinking palliative. So all the active options are gone, patient is riddled*

with cancer and bedridden most commonly and starting preparing for end stage of life.”
(9)

- *“I would say when the patient is not responding to treatment.”* (10)

4.3.6.3 Training of oncologists in palliative care

Four oncologists commented on their training experience in palliative care. They admitted that their main training was focused on the active treatment of cancer and not on palliative care. Most of what they know about palliative care was self taught from text books and was gained through experience.

- *“Emotionally it’s very draining managing patients with incurable disease specially when you’re also spending a good part of your day managing patients with active management for their cancer which is really the bulk of our scientific and academic training was around.”* (4)
- *“At the moment we..I...we will just use our text books, you know, like Oxford handbook or whatever.”* (5)
- *“For a oncologist it’s a...we don’t feel being a expert in the field when it comes to palliative care.”* (14)
- *“Our palliative care training is also poor. It’s not part of, you know, we’ve been taught how to offer chemo and how to give radiotherapy but beyond that, you’re not taught, so it’s self taught.”* (15)

4.3.6.4 Palliative care setup at treatment units

The participants were requested to comment on the availability of palliative care facilities at their treatment units. Eight oncologists admitted that there is no formal palliative care teams present at their units.

- *“We don’t currently have a separate palliative care facility although that is something that we would obviously like to work towards. Uhm, so our palliative care is....fall under the same umbrella as our oncology services.”* (1)
- *“We have none. We are the palliative care team (laughing).”* (4)

- *“We don’t (laughing) we don’t really have a palliative care team, I mean, in the unit we don’t have a dedicated palliative care team.” (5)*
- *“We don’t actually have a palliative care team at the unit.” (6)*

Fourteen oncologists indicated that the provision of palliative care to patients with advanced disease is usually a combined effort launched by the staff members already present at the unit, namely the oncologists themselves, a social worker, a physician extender, medical officers, chemotherapy nurses, radiographers and the administrative staff that deals with the patients.

- *“It’s a multidisciplinary team, uhm, consisting of ,uhm, social workers, chemotherapy sisters, uhm, radiographers....the clinical staff and admin staff also play a role in terms of supporting patients and been aware of their needs, and then also medical officers and other oncologists in the group as well.” (2)*
- *“The team comprises really everybody in the unit, everybody plays a role. One is depended on the other, from the receptionists to the doctor really. Those who actually will have a conversation about palliative care would obviously be the doctor and the oncology social worker and probably the, uhm, the physician extender.” (8)*
- *“It’s basically the oncologists, uhm, medical officer, a social worker, and then we have, what we call physician extenders who are very closely involved and they actually liaise quite often with the patients when they come in or walk in or phone with complaints.”(11)*

Eleven oncologists mentioned that outside services such as local hospices and the patients’ general practitioners are also involved in the provision of palliative care to their patients.

- *“The GPs are often involved more so with particular patients and hospice.” (3)*
- *“And then we make use of outside, uhm, outside things like hospice but they’re not actually part of a team within the hospital.” (5)*
- *“I can’t do palliative care without the GP. In South Africa, the infrastructure is such that the GPs are important.” (11)*

- *“We have very close ties with the hospices in the area....we meet with them once a month. One of the sisters comes here and then we discuss all patients that have been referred to hospice to give feedback from their side and us to them.” (13)*
- *“A large part of our patients from here are from outside the district...there involve the patient’s GP.” (15)*

4.3.6.5 Shortcomings in the current palliative care services

A number of shortcomings experienced in the current palliative care systems at the participants’ units emerged during the interviews.

One oncologist was of the view that the general lack of palliative care facilities in the country can unnecessarily prolong anticancer treatment.

- *“I think what happens in a lot of countries and also including in South Africa is because of a lack of palliative care facilities we..we tend to hang on to the patients and try and offer them treatments up till a situation where you know we get told by the medical aids that we treat up till death.” (12)*

Five oncologists mentioned problems they experienced with their local hospice services. These problems included communication issues, additional administrative work, unavailability of beds as well as a reluctance of patients to be referred to hospices.

- *“There’s still, you know, certainly early on in a patient’s course of their disease, there’s still despite all of that quite a....quite a reluctance to accept a hospice referral.” (4)*
- *“The hospice is also very thin at the moment so there is a lot of need, much less than is available or much more need than what’s available.” (7)*
- *“I think there’s a big wall between us and hospice for instance. There’s not really good communication. I don’t feel like always phoning them. It’s difficult to get hold of them, they make very nasty comments about us (laughing), so there’s not good, there’s no good relationships there and it’s a lot of crap, all the admin involved with it.” (9)*
- *“The hospice facilities are not able to, you know they don’t have beds for those patients.” (12)*

Two oncologists mentioned that the lack of palliative care leadership and the fact that the oncologist often is the sole provider of palliative care puts a lot of pressure on the treating oncologist.

- *“You know, you’re head of the team and you become responsible and I think my mistake was initial to do all of these and you end up burning out yourself and now I just try to at least be a good doctor but I feel the team, there is not good leadership in palliative care right now.” (9)*
- *“But it puts a lot of burden on, you know, on the treating physician because, you know, you then do take on that palliative part and, you know, not having facilities, I mean we try...you know you admit into the hospital but, you know, the patient cannot stay there for long periods of time.” (12)*

Three oncologists expressed concern regarding the lack of palliative care knowledge of some general practitioners and ward staff members.

- *“Our patients who land up here, you know, it’s a rotating staff, they don’t have oncology training and they don’t always understand, you know, that morphine is to be given, you know, on time, and, uhm, so the care is not what it should be.” (12)*
- *“You know my honest feeling is that the palliative care should be the family physician’s job and not the oncologist’s job and if we could change that it would be great but unfortunately in this town, we find that most of the GPs feel uncomfortable.” (13)*
- *“And also the interface between palliative care...between general practitioner and oncologist, I think there is also quite a gap.” (15)*

One oncologist mentioned that some patients feel abandoned when they are referred to general practitioners or to specialists in palliative care.

- *“Unfortunately lots of patients feel that they’ve been abandoned by the oncologist if you pass the care on to the GP or to a palliative care doctor.” (15)*

4.3.6.6 Recommendations to improve palliative care facilities currently available at treatment units

The participants were asked to give suggestions on how the palliative care facilities available at their units could be improved.

a) Involving the patients' general practitioners

Eight oncologists suggested that the patients' general practitioners should be more involved in their care. They could assist the oncologists with symptom management and palliative care as well as the administrative work associated with advanced disease patients. In order to improve continuity of care the general practitioners should receive palliative care training and communication between them and the treating oncologists should be enhanced.

- *"We need to enlist general practitioners and provide training in palliative care so that they can become more involved in ongoing care of patients... particularly looking at symptom control and then terminal care and trying to have as many patients managed in their home setting as suppose to an inpatient facility." (1)*
- *"I suppose just communication with the GPs, cause they're important as well, uhm, and that is sometimes you would admit the patient to the ward and not necessarily have the GP involved as much, so I suppose we could look at that." (3)*
- *"And then just around the administrative point of that, we often get requests to do, uhm, scripts for morphine example....I also think GPs need to be educated into how to prescribe it and that they also have to write motivational letters as we do all the time. So the involvement of the GP here is something that I would like to see happening." (13)*

b) Early referrals to hospices

Three oncologists suggested that patients should be referred to hospices for symptom management and support at an earlier stage.

- *"Try and get earlier referrals to hospice because I find once they become involved, they take over this sort of day to day management, so especially for pain control where*

dosages of morphine needs to be adjusted twice a day sometimes even, they're very good at that. Uhm, in our busy practice it's quite difficult to take that private phone call twice a day. (3)

- *"We fortunately that we have a good hospice backup, so I tend to want all my patients who are being managed palliatively to be referred to hospice so we're really try and emphasise that rather earlier rather than later." (15)*

c) Employment of a palliative care physician

Five oncologists suggested that palliative care physicians be employed to assist with the management of advanced disease patients. Their presence provides the oncologists with valuable additional time to devote to anticancer treatment. It will also ensure an early smooth transition to palliative care and will guarantee the availability of help and advice regarding palliative care issues. They could also act as leaders of palliative care teams and ensure proper communication between team members.

- *"I think that our unit and any unit would...would be much richer and would offer a far better service, uhm if we had specialist palliative care physicians who were able to, uhm, to help us manage our patients. I think it would free up a lot more of our time to deal with our active patients and I think the patients would benefit from having a palliative care service that isn't sort of just tagged on to the end of their treatment but is actually, you know, an integral part of their cancer journey." (4)*
- *"I think we need a palliative care physician or, uhm....in the UK we hadthey were not based at our hospital but they came around....for ward rounds twice a week. They gave us advice, we could always phone them about syringe drivers, you know, some people are very agitated a few days before they die and what to put in the syringe drivers for example." (6)*
- *"And to have a palliative doctor, just somebody in specific areas where we can say this guy is doing palliative care and please, he's managing my terminal patients that would be such a relief you know and doing that thing of talking to the GP and get the*

psychologist or whoever or just to be captain of the team in palliative care because at this stage people are fighting about who's the captain." (9)

d) Providing exclusive palliative care services

Four oncologists suggested that exclusive palliative care services should be provided to patients by a multidisciplinary team in a caring environment.

- *"Like there would be units overseas that will have like...you'll have a clinical round than you'll have like a you know like...either a palliative round or it will be all the allied specialties like, you'd sit down at a table with the dietician and the O.T. and the physio and the social worker and counselor and you'll just talk about other aspects to the patient and what you all been going through looking after them, which is probably what you should try and do for the difficult patients but it's probably a time thing." (5)*
- *"What I really would like to see is that there is a facility that one can actually, you know, put a patient there and you know that they're going to be looked after by caring staff. So there is a real need for, you know, somebody who's caring and, you know, quiet environment and can, you know, be there with the patients and give them the treatment and turn them and do all that you know. So there's a huge need for that." (12)*

e) Employment and training of medical officers and nurse practitioners

Five oncologists suggested that medical officers and nurse practitioners trained in palliative care be employed to help with the management of patients with advanced disease or, alternatively, that current staff be appropriately trained.

- *"Maybe we must train nurse care practitioners like the St Luke sisters, but I mean for our own unit and to manage our own patients here and at home type of thing, uhm, I think that would be very valuable." (6)*

- *“I think if we can equip our medical officers to be...to be trained, that would be superb because, I mean, I think, the oncology...the oncology training is such that we should actually be focused on active treatment.” (11)*

f) The presence of an oncology social worker/counselor

Two oncologists were of the opinion that the availability of an oncology social worker/counselor at the units for counseling and support is invaluable

- *“I think probably would be good to, hmm, make sure that all the patients who need, hmm, counseling get to see the oncology social worker.” (8)*
- *“I think that no unit can consider running as a fully functional unit without a counselor. So I know that in some units there is discussions saying that the counselors actually don’t make financial sense because they are not bringing in anything but if you try and work as an oncologist without the counselor, you’re not gonna cope, you actually gonna burn out because they’re taking a big load off your shoulders. So I try and insist that all my new patients at least meet her and then especially with the palliative patients.” (15)*

g) Making use of palliative care guidelines

One oncologist emphasised the value of having guidelines pertaining to palliative care issues and symptom management available at their units.

- *“If you have your own sort of unit guidelines in terms of how you manage like pain or malignant bowel obstruction, that will probably also help, you know. It will teach you and it will probably make the care a bit more uniform as well, so that’s maybe something that units could do.” (5)*

4.4 Conclusion

The information set out in the paragraphs above were distilled through the careful review and analysis of data which were collected by means of in depth, semi structured, face to face interviews with fifteen radio-oncologists who specialise mainly in solid tumors. Six main themes which all have a bearing on the main topic as well as sub categories were deduced from the data through a process of coding. All the themes and sub categories were described by using a narrative approach based on relevant quotes from the interviews. A summary of the collected data is presented in the network display below.

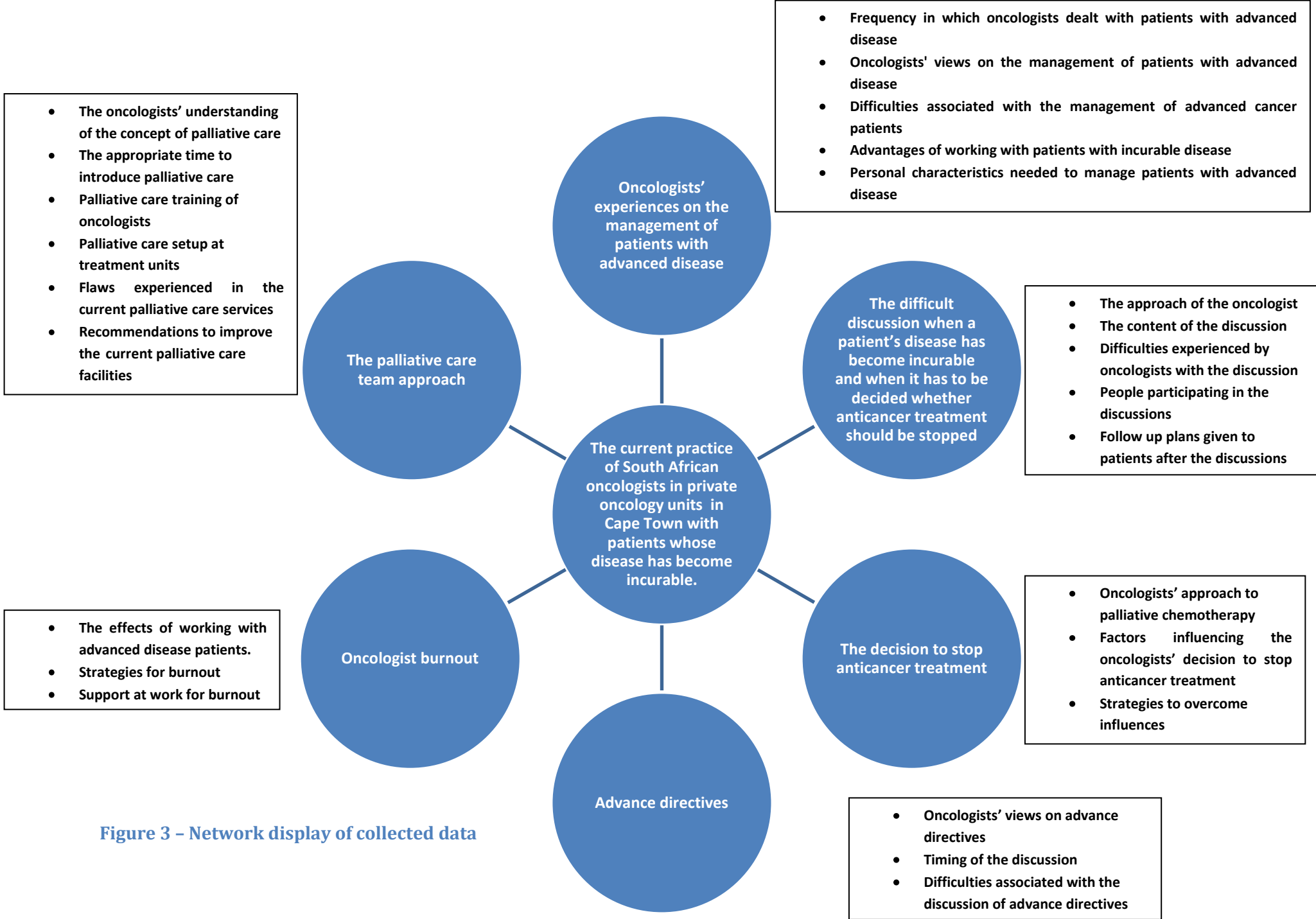


Figure 3 – Network display of collected data

CHAPTER 5: Discussion

5.1 Introduction

Managing patients whose disease has become unresponsive to anticancer treatment is a complicated but integral part of any oncologist's daily programme. Despite the satisfaction associated with the curing of patients from their disease, with the monitoring of patients in remission or with the successful controlling of patients' advanced disease, there will eventually come a time in every oncologist's career where some patients' disease will no longer respond to anticancer treatment. The results of the researcher's study provide strong evidence that the management of patients with advanced disease in the private oncology sector in Cape Town, South Africa presents complicated challenges. These challenges should be addressed appropriately to enhance patient care and to improve job satisfaction for the treating oncologist. Relevant topics associated with the management of such patients have been identified from the data gathered during the study and will be discussed in the sections below.

5.2 Oncologists' experiences regarding the management of patients with advanced disease

It was evident from the responses and demographic data that the management of patients with advanced disease is common practice amongst oncologists in the private sector. For the majority of the participating oncologists it constitutes a major part of their daily work. This corresponds with ESMO's survey on oncologists' involvement in and attitude towards palliative care. Sixty nine percent of the respondents in that survey reported that their practices included patients with advanced disease.¹ In the present study, the lack of adequate palliative care services was commented on while insufficient screening facilities in South Africa were proffered as a possible reason for the high incidence of patients with advanced disease.

The management of patients with advanced disease was perceived as a very challenging activity, fraught with complicated issues and difficult problems. The admission by most respondents that the management of such patients, which constitutes a major part of their daily workload, is not an activity favoured by them is a cause for concern. This may reflect a negative attitude of the participants towards palliative and end of life care or may indicate the

existence of the notion that this particular aspect of the participants' careers is emotionally draining and may lead to burnout. However, such a perception differs from the results of ESMO's survey in which most oncologists indicated that they derived satisfaction from their involvement with palliative and end of life care.¹ Possible reasons for this perception amongst the participants in the current study could be the variety of difficult issues and challenges associated with the management of patients with advanced disease or the lack of training in palliative care, as stated by some respondents. Training in palliative care could not only improve the management and care of these patients but could also change the oncologists' negative attitude towards this particular field by the development of coping skills which may help oncologists to experience the satisfaction that comes with the implementation of palliative care.

The respondents experienced the management of young patients with incurable disease as especially difficult to handle. The determination of these patients to keep on fighting their disease despite bleak prospects affected the oncologists emotionally. Oncologists with young children of their own and who, therefore, were able to relate more intensely to such patients, were affected most. Oncologists also experienced the management of patients to whom they became attached as very difficult. Similar difficulties were experienced with the management of patients who reminded the oncologists of a friend or family member or whose personalities were compatible with their own. The various degrees of distress experienced by patients with incurable disease and by their family members may also render their management more difficult. A great deal of time and effort need to be spent with these patients and their families to address issues and concerns and to provide compassionate support, especially in cases where denial is present. Such encroachment on the already limited time available in the daily schedules of the oncologists is aggravated by the extra paper work, of which the completion of referral forms for hospice and healthcare at home are examples, and administration usually associated with palliative care. This adds unwelcome additional pressure on the treating oncologist.

Despite all the difficulties associated with the management of patients with advanced disease, the respondents did mention some rewards that were associated with this experience. Some respondents regarded the interaction with patients and their family members to ensure that everyone is well informed as fulfilling. Others experienced the effective control of their patients' symptoms and the management of the complex associated issues as satisfying. One respondent was of the opinion that these rewards experienced could be enhanced by the improved confidence that would be associated with their further training in the field of palliative care. In short: A dedicated compassionate oncologist who is passionate about his work and especially about palliative care would be able to thrive under these taxing circumstances.

5.3 The difficult discussion when a patient's disease has become incurable and the decision whether anticancer treatment should be stopped

From time to time every oncologist is faced with the difficult decision on whether the anticancer treatment of a patient with advanced disease should be terminated or continued. These decisions are usually made by the oncologist after a comprehensive discussion with the patient and his family members regarding the disease status, the clinical rationale for stopping treatment and the approach to be followed with continued care. It is imperative that patients be made aware that further anticancer treatment options may cause more harm than good, especially when their disease is advanced. The possible benefits and harm of anticancer treatment should be carefully considered and discussed to effectively apply the ethical principle of beneficence and non-maleficence. It is clear from the nature of the responses from the participants that this topic is regarded as an extremely important and arduous aspect of the management of patients with advanced disease

After having the difficult discussion with their patients regarding their recent disease status, a complicated decision needs to be made regarding continuation of anticancer treatment or not. The oncologist's perception of palliative chemotherapy together with influential factors which were gathered through the interviews can affect his judgement on this particularly important decision.

5.3.1 The approach of the oncologists towards the difficult discussion

Most oncologists believed that an open and honest approach should be followed during the difficult discussion regarding the decision to stop anticancer treatment. They felt that information should be given in a clear and sensitive manner in understandable non-technical language. These findings correspond with the oncologists' descriptions of communication with patient and family regarding end of life care in the study performed by Jackson *et al.*⁵⁹ Enough time should be set aside for the discussion to enable the oncologist to address all concerns and answer all possible questions of the patient and family members. This again accentuates the time constraints associated with this particular field which inevitably add to the stress burden of the treating oncologist, particularly on a busy day. It furthermore emphasises the value of following the team approach. The assistance of a social worker or palliative care physician could relieve much of the pressure on the treating oncologists during these difficult discussions

Some oncologists expressed the opinion that the issue regarding the cessation of anticancer treatment and the commencement of best supportive care should be broached early in the disease process of a patient who presents with advanced disease. Such an approach is positive as it enables smooth transition from curative to palliative care and provides an early opportunity to discuss any issues regarding the initiation of palliative care services such as hospice referrals. Early discussions regarding the initiation of palliative care will also enhance early referrals to palliative care services which, in turn, will improve quality of care. These positive findings differ from the findings of Cherlin *et al* which showed that oncologists tend to inform their patients that their disease have become incurable only late during their disease process. This allowed little opportunity for palliative care discussions and hospice referrals.⁶⁰

Mutual trust was also believed to be a vital component that needs to be present between oncologists and patients to ensure better management of these discussions. A relationship between oncologist and patient which is based on mutual trust will enable the oncologist to get to know their patients' personalities and to judge their ability to understand their situation. Building trust is usually much easier if the oncologist has been involved with the patient's care over a long period. This will give the opportunity for trust to build steadily and to evolve with each consultation.

Most respondents emphasised that it is crucial in the management of patients with advanced disease that realistic hope be given when anticancer treatment needs to be stopped. Patients need to believe that there is always something that can still be done although the aim of treatment is no longer seen as curative. This is by no means the end of the road for these patients but only a transition into a new phase in their lives, as one respondent aptly stated. Unrealistic hope for a cure should rather be displaced with a more realistic hope for a life without pain or distress and the realisation of rational aims such as spiritual peace or ordering affairs, as stated by Daneault *et al.*²⁴ These patients should therefore be motivated and encouraged to live their lives to the fullest and make the most of the time they have left.

5.3.2 The oncologist's approach to palliative chemotherapy

The oncologist's perception of and approach to palliative chemotherapy can have a major influence on the decision to stop anticancer treatment in patients with advanced disease. It may even cause the inappropriate prescription of aggressive chemotherapy. It was reassuring, however, to learn that some of the participants' views regarding palliative chemotherapy became more conservative as they gained more experience. They gradually recognised that the exposure of vulnerable patients to life debilitating toxicities was unacceptable, especially where the aim of treatment is palliation of symptoms. This view was also held by Kao *et al* in their review of deceased oncology patients treated with palliative intent.²²

The notion that gaining experience caused the participants' approach to become less aggressive is appropriate. In the treatment of patients with advanced disease, doing nothing in terms of chemotherapy can sometimes be regarded as good management. Thus, these participants were of the view that older, more experienced oncologists can play an important role to guide younger oncologists, who generally are more aggressive in their treatment decisions, to adopt a more thoughtful and cautious approach when deciding on the continuation of treatment of patients with advanced disease. Awareness of the value of holistic palliative care, which does not necessarily have to include palliative chemotherapy, could thus prevent the prescription of inappropriate chemotherapy which could improve quality of care.

5.3.3 The content of the difficult discussion

The content of the discussion that oncologists have with their patients when their disease becomes incurable was commented on in detail by the participants. Back, Peppercorn and Hagerty *et al*^{32,35,64} outlined the information that should be provided to and discussed with patients during such sessions. It should pertain to prognostication, possible treatment options available with their related efficacies and toxicities as well as to a future care plan which has to correspond with the patients' needs and preferences. The fact that most oncologists discussed with their patients the survival benefits of available treatment options together with associated toxicities was reassuring. This will enable the patient to take a better informed decision to consent to the continuation or cessation of certain anti-cancer treatments and not to desperately grasp at treatment options with low possibilities of success. Thus unnecessary aggressive treatments which may affect quality of life can be prevented. This finding differs from the analysis done by Audrey *et al* who found that most patients were not clearly informed about the survival benefits of palliative chemotherapy.⁶¹

The majority of the oncologists who participated in this study also mentioned using special investigations such as CT-scans and blood results to convey the message of their patients' disease status. This method of conveying disease information is sound as most patients in this situation experience fear and anxiety regarding their illness which can affect their attention and comprehension when information of a sensitive nature is presented to them. In these situations the special investigation reports serve as concrete evidence and visible proof of disease progression and will help patients to accept and understand their current condition. One participant emphasised that the provision of written information regarding their disease status and end of life care to patients is an essential element of good doctor-patient communication.

Some oncologists pointed out that the discussions they had with their patients further provided the opportunity to discuss referral to palliative care services and also prevent unnecessary exposure to cytotoxic treatment regimes. The importance of regular follow up visits with their patients after anticancer treatment had been stopped was further underscored by a number of oncologists. This concurs with the findings of Fujimory *et al* which indicate that participating patients regard continuation of physician care in a changed treatment plan as important.⁶³

Continued physician involvement will ensure that patients will not feel abandoned by their oncologists even though anti-cancer treatment has been stopped and main care has been handed over to other treating modalities such as hospices or general practitioners. During this phase of treatment the oncologist can concentrate, together with the other role players, on symptom management and quality of life care.

Although the data suggested that the content of the difficult discussion that the participants had with their patients when their disease became incurable was comprehensive and thorough, the participants did not mention whether this was regular practice or only a description of the ideal situation. Furthermore, it was evident that certain preferences of patients, as identified by Hagerty and Peppercorn *et al*, had not been attended to.^{34,35,64} The participants did not mention whether they assessed and addressed any fears, concerns or wishes that their patients might have mentioned during these conversations. They also did not mention whether the extent of the information and the timing of the communication had first been negotiated with their patients or whether the patients' permission had been requested before such information was discussed. According to Hagerty *et al*³⁴ these preferences are important as there has been an increasing predilection of cancer patients in developed countries to become more involved in the decision making process regarding their care as well as a consequent demand for more detailed information regarding their disease's prognosis. However, such shortcomings can be overcome with adequate training and raising of awareness regarding the importance of ascertaining patient preferences in good time.

5.3.4 Factors influencing the oncologists' decision to stop anticancer treatment

After having the difficult discussion regarding the advanced state of a patient's disease, a complicated decision needs to be made whether anticancer treatment will be continued or stopped. Numerous factors which may influence this important decision were mentioned by the participants

Most oncologists commented that tumor response to anticancer treatment is a very important factor to consider when deciding on cessation of treatment. Non responders to previous lines of chemotherapy were believed to have especially a lower overall survival rate when compared

to patients who have responded. This important information should be communicated to the patient during the decision making process to enhance acceptance of his situation. International guidelines should also be followed when prescribing palliative chemotherapy and discussed with the patient. Patients might find it easier to accept their disease status when they know that no further treatment options are available.

Patient factors were also reported to have a strong influence on the decision to stop anticancer treatment. Especially patient tolerability and performance status should always be assessed and taken into consideration when deciding on further possible treatment. If the patient is not able to tolerate the toxic side effects associated with the treatment or if their performance status are influenced to such an extent that they stay mostly in bed, then continuation of treatment should be reconsidered. This approach is especially important when the aim of treatment was to improve the patient's symptoms and quality of life. Each patient should therefore be assessed individually before prescribing palliative chemotherapy and the expected risks and benefits of the chemotherapy should be taken into consideration, as stated by Napa and Siato *et al.*^{66,68} Once again, the application of guidelines that will help oncologists to determine whether their patients are fit for treatment will be very useful, as recommended by Napa *et al.*⁶⁶

Most oncologists also believed that the patient's preference for treatment should be taken into account and be respected, provided that the patient is well informed. This could be complicated as some patients' ability to reason might be affected by emotions, family members or the advanced state of their disease. Oncologists should therefore guide their patients in their decision making process by taking into account any possible needs or concerns they might have. Patients should be made aware of the aim of treatment and possible influences that the side effects of the chemotherapy might have on their quality of life. Oncologists should reinforce if what the patient has decided, in their view, is acceptable but, at the same time, should keep in mind that despite their own views regarding their patients' treatment decisions, patient autonomy is very important and should always be respected.

Patients, together with their family members, can also have a great influence on the oncologist's decision to stop anticancer treatment. Some participants believed that most of their patients can easily be influenced by close family members especially siblings, whose goals and wishes may differ from theirs. These family members, who may be in possession of information and data gathered from various resources, can exert pressure on the treating oncologists to continue treatment even if the outcome might be futile. Additional pressure can be exerted by a patient who, in turn, is influenced by his family members who, inappropriately, want to keep on fighting. Oncologists should therefore make sure that a family member is present when further treatment options are being discussed and that the social workers interact with and support the family members. Wishes and concerns of both the patient and family members should be addressed to prevent any misunderstandings and to make sure everyone is equally informed and in agreement. The oncologist should also adhere to his guidelines and honestly disclose all relevant information about prognosis and treatment outcomes without being influenced or manipulated by the patient or his family members. Most participants believed that a trustful and honest relationship with the patient and his family together with effective communication holds the key to alleviating the problems usually associated with the decision to stop treatment.

Most participants admitted that working in the private sector can have an influence on their decision to stop anticancer treatment. More treatment options are at the private oncologist's disposal than the oncology regimes available in the government sector. Although these treatment options may be less effective, their mere availability may easily influence the private oncologist to prescribe them rather than having the difficult discussion regarding cessation of treatment and initiation of palliative care. This was also noted by Kao *et al.*²² Reassuringly, some participants acknowledged that these multiple chemotherapy lines available are usually strictly regulated and should be prescribed appropriately. Participants also believed that patients should be made aware that, although there are more treatment options available, their effectiveness cannot be guaranteed. Even if the patient responded to these treatments, the chances of cure still remain poor.

Additional pressure is reported when funding for these treatment options from certain medical aid schemes are not available. Oncologists are then forced to stop anticancer treatment due to lack of funds and not by choice. This may be very difficult to communicate to the patient or his family. Additional time, stress and effort may also be consumed to motivate for the approval of funds by medical aid schemes for these possible futile but lucrative treatment regimes. Although participants believed that great caution should be applied not to waste limited resources on these potential futile treatments, some believed that flexibility should be applied in exceptional cases such as to provide time to the patient to experience the birth of a new grandson or the marriage of a daughter. Each patient should therefore be assessed individually to determine if the necessity and benefits of these treatments are strong enough to outweigh the potential side effects and futility associated with them.

5.3.5 Difficulties experienced by oncologists with the discussion

Communication hurdles associated with the difficult discussion that oncologists have with their patients when their disease becomes incurable, were identified during the interviews. The patients' inability to accept their disease status and their loss of hope if no cure is available were regarded as common problems that usually arose during these discussions. The participants felt that if they acknowledged to their patients that anti-cancer treatment should be stopped, they may be regarded as a failure. They believed that their patients perceived them as doctors that will cure their disease and, therefore, they should give everything to uphold this perception.

Patients also found it very difficult to accept information indicating that there are no more lines of treatment available for their disease. They will even refuse treatment if the treatment aim is enhancing quality of life and not life extension. Young patients, in particular, will grasp any opportunity for cure, even if the chances thereof are very slim. This was also evident in the study performed by Matsuyama *et al* which indicated that patients with advanced cancer were inclined to opt for chemotherapy even if only a minor health benefit might materialise.⁷⁰ The participants found it difficult to manage the emotional outbursts and reactions by patients and their family members when receiving the news; the different points of view between the patient and his family regarding further treatment as well as the mixed messages received by

family members who were not present at the consultations. It is of utmost importance that all concerned family members attend these consultations together with the patient to address issues regarding further treatment options and to prevent any future discrepancies.

The participating oncologists experienced difficulties in the management of the communication hurdles associated with the discussion to stop anticancer treatment. The complexities of each hurdle together with the time constraints that are usually associated therewith were proven to be quite challenging. These hurdles may further influence the treating oncologists to provide inaccurate prognostic information to the patient which may lead to the prescription of possible inappropriate aggressive anticancer treatment. Oncologists should perhaps embrace both biomedical and psychosocial aspects of care as suggested by Jackson *et al.* Oncologists that did so were proven to communicate more clearly about end of life care; felt more satisfied with the care they provided to terminally ill patients and their families; did not regard progression of the disease as due to personal failures and also felt less burnt out. They also understood that these conversations should take place on numerous occasions during treatment to provide more opportunities for closure and emotional support.⁵⁹

5.3.6 People participating in the discussions

Most oncologists prefer that a family member or care giver should be present when they inform their patients that their disease has progressed beyond the realms of cure and that treatment should be stopped. Discussing bad news regarding the status of his disease with the patient can be very traumatic and stressful which can affect the transfer of information. Family members or care givers can assist patients by relaying information which may be missed due to anxiety or disease related fatigue. They can further act as a form of support for the patient when bad news is delivered. Most patients also preferred to have a family member or care giver present during these conversations, as reflected in the systemic literature review performed by Hagerty *et al.*³⁴

The presence of an oncology social worker during these conversations was also regarded as important by the participants. Not only will they give extra support to the patient and his family but they can also assist in explaining medical terminology with which the patient may be

unfamiliar. Not all oncologists regarded it as necessary for the social worker to attend all these consultations. It might be logistically difficult especially if these discussions occur unforeseen, for instance when a routine follow up scan reveals disease progression. Some oncologists will only consider possible engagement of a social worker if the discussion indicates that it will be appropriate for one to be involved. The oncologist will then, after the discussion, first confirm with his patient that he will require the assistance of a social worker before making the necessary arrangements with a social worker. The contribution by an oncology social worker could also be more beneficial if she is involved earlier in a patient's disease process, even when cure is still the aim. This would enable a smoother transition to supportive care due to the better understanding of the disease process which the patient would obtain through the extended counseling. It would also allow a more effective use of the social worker's skills as the patient's illness progresses.

5.4 Advance directives

Advance directives play a very important role when a patient's disease becomes incurable. It guarantees that the wishes of patients are respected with regards to future care and treatment in scenarios where they are not able to decide for themselves. This is especially evident in situations where a patient's condition deteriorates rapidly and where decisions regarding further active treatment need to be taken on behalf of the patient who might be too weak to decide. It was therefore disturbing to notice that although a minority of the participants believed that discussing advance directives with their patients are important, most of them admitted that this is usually neglected and not routinely done. Possible reasons given were demanding time constraints associated with these discussions as well as the unwillingness of patients to engage therein because they feel they are not ready yet. This was also shown in the study of Kierner *et al* who reported on the poor interest shown by patients in advance directives due to inappropriate timing of the discussion.⁷¹

The participants also felt that broaching the subject of advance directives would imply that active resuscitation would be inappropriate and, therefore, would not be performed when a patient's disease had become advanced. Although participants would still continue to support

their patients and manage their symptoms, high care management such as intubation and ventilation would only be appropriate if the reason for deterioration of their patients' conditions is unrelated to their advanced disease. If not communicated well, this view can potentially cause great stress and uncertainties in situations where a patient's wishes are to continue active treatment or where family members are unaware of the advanced state of the patient's disease. Participants felt that discussion of advance directives with the patient and his family can help to prevent these uncertainties and decrease pressure on the oncologists when decisions need to be taken on whether a patient needs to be actively resuscitated or not. The chances are that most patients with advance directives do not want active resuscitation or invasive procedures to prolong their life but only procedures to manage their symptoms and improve quality of life. This was confirmed by Kwon *et al* in their study of the advance directives for terminal cancer patients.⁷⁵

It was evident from the data regarding the timing of the discussion of advance directives that the participants did not approach this subject with urgency. Most participants will wait for patients or their family members to raise the topic before discussing it. This approach may essentially rule out this discussion because some patients and their family members might not be aware of this practice or, if aware thereof, may be reluctant to participate in such a discussion in fear of accepting the advanced status of their disease. Some participants will wait for their patients' disease to become resistant to anticancer treatment or for their condition to deteriorate to such an extent that an arrest is anticipated before broaching the topic. This may complicate the discussion because patients in these situations tend to be more reluctant to have this conversation, as proven by Kierner *et al*.⁷¹ International perspectives are that advance directives should be discussed early and frequently in a patient's disease process. Regrettably, only two participants held this view. Such an approach will provide frequent communication opportunities to discuss the patient's disease process and to address any concerns or uncertainties. It will further give the patient and his family enough time to process the information and plan for the road ahead. The discussion regarding the implementation of palliative care could also be brought into the conversation which could lead to early referral to palliative care services and eventually improvement of quality of care.

5.5 Oncologist burnout

Burnout is found to be quite common amongst oncologists due to the nature of their work. It is a serious condition which can affect their physical health as well as their interaction with colleagues or family members. If left untreated it could seriously influence their ability to provide quality of care. It was alarming to learn how the management of patients with advanced disease affected the participants emotionally and physically. Most participants commented overwhelming about the emotional strain and physical exhaustion they experience when dealing with patients with advanced disease. These symptoms affected their daily work as well as family life by causing them to be frequently irritable, frustrated, physically exhausted and more prone to emotional outbursts towards colleagues and family members. Emotional exhaustion and frustration were proven to be two major signs of oncologist burnout, as stated by Allegra *et al.*⁸³ It is strongly suspected, therefore, that these participants may be experiencing a degree of burnout.

It is reassuring that the participants were well aware of the importance of recognising burnout and that they had strategies in place to prevent or overcome it. Most participants believed in taking regular breaks and holidays to get away from the stressors of work and to recharge. These strategies were also identified by Allegra, Whippen, Swetz and Granek *et al.*^{83,84,86,88} A good strategy mentioned and which was also referred to by Lyckholm⁴⁸, is the sharing of afterhours calls and having one half day in a working week off for personal matters. This is an important advantage of the sharing of an oncology practice with other oncologists and should be recommended. Extra-occupational interests such as outdoor activities, hobbies, exercising, travelling, gardening, sports and spending time with the family were also regarded as good measures to prevent burnout and concurred with the findings of Swetz *et al.*⁸⁶ Some participants believed that emotional distance from patients, especially if they have advanced disease, may prevent burnout while another believed that delegating work may ease the pressure.

Support for oncologists in their efforts to cope with burnout was also seen as important by the participants. Most participants derived support by debriefing amongst each other in their units

or from their family members at home. It was alarming to learn that private companies employing oncologists as a rule do not provide much support to oncologists to prevent burnout. An oncology social worker is present at the units when needed, however, no formal debriefing for burnout was provided by the participants' company. Some participants were appalled with this situation and felt that they were let down by their company in that respect. The only support given by the company to prevent burnout was to provide leave and sabbaticals. Some participants felt that time constraints and overloaded working schedules prevented any participation in whatever support is provided to lessen burnout. Overloaded working schedules are seen by Shanafelt and Allegra *et al* as major causes of burnout.^{47,83} Therefore it is suggested that possible ways in which the participants' institutions could support them in the prevention and treatment of burnout should be investigated. It could include training and provision of information, acknowledgment and validation of grief and institutional psychosocial support, as recommended by Granek *et al*.⁸⁸ According to Lyckholm,⁴⁸ the formation of clinical health teams where team members can clinically and emotionally support one another and hold regular meetings for debriefing can also be very valuable. Adequate training in palliative care can assist oncologists to develop competence and confidence in managing patients with advanced disease so that the personal and professional satisfaction in helping these patients and their families mitigate against burn out.

5.6 The oncologist's understanding of the concept of palliative care

It was evident from the responses of the participants regarding their understanding of palliative care that the majority were not familiar with all the aspects of palliative care as set out by the World Health Organisation.²⁷ Most participants felt that palliative care encompasses mainly symptom management with a focus on quality of life and not cure while others thought that psychosocial support should also be added. Only one participant saw palliative care as a holistic approach to patient care incorporating symptom control, psychosocial and spiritual support together with ongoing management of the patient's disease. None of the participants mentioned support for the patient's family in their comments. This unfamiliarity with the field could be due to a lack of training received in palliative care. Some participants admitted that their main training was focused on the active treatment of cancer and not on palliative care.

Most of what they know of palliative care was self taught from text books and was gained through experience. These statements correlate with findings of the ESMO's survey on oncologists' involvement in and attitude towards palliative care. According to the results of this survey participants admitted that they had not been adequately trained in the field of palliative care.¹

Despite the lack of training in and familiarity with the field of palliative care, reassuringly most of the participants suggested that palliative care should be implemented early in a patient's disease process. This will ensure smooth transition from curative treatment to palliative and supportive care. The participants also believed that palliative care should coexist with active anticancer therapy to ensure the continuum of care. These findings concurred with the study done by Bakitas *et al* where clinicians valued the introduction of early palliative care in concurrence with oncology treatment.⁵⁵ However, none of the participants saw palliative care as only palliative chemotherapy or radiotherapy. Unfortunately a small number of participants were of the view that palliative care should be introduced only when a patient does not respond to active treatment anymore and has moved into the preterminal phase of his disease. This once again emphasises the lack of training in and understanding of palliative care. Training opportunities should therefore be made available for oncologists to improve their understanding of palliative care and to stimulate an interest to ensure proper management of patients with advanced disease.

5.7 Palliative care setup at treatment units

Numerous studies have shown the advantages of following a multi-disciplinary approach towards providing palliative care to patients with advanced disease.^{44,45} It embraces different frameworks and approaches to adequately manage the complicated needs of these patients. According to studies performed by Temel and Muir *et al*^{3,56} embedding a palliative care clinic in a private outpatient oncology unit has the potential to further improve symptom control and care for patients while providing support to the treating oncologist. It was therefore alarming to note that, despite these positive findings, most participants admitted that no formal palliative care teams exist in their units. They see themselves as the main providers of palliative care.

They do however agree that having a specialised palliative care team present in their units would be a positive goal to strive for.

The provision of palliative care was mainly regarded as a combined effort launched by the staff members already present at the units. These staff members included oncologists, medical officers, physician extenders, social workers, chemotherapy nurses, radiographers and administration staff. Every staff member who has regular contact with patients becomes aware of the patients' needs and provides support in some form or another. However, the actual communication about palliative care would be performed by the doctors, the oncology social worker and physician extender. Although certain specialties such as physiotherapists, counselors or spiritual advisors were missing from the current palliative care setup at the units, the participants did mention the utilisation of outside modalities, such as hospice referrals and the patient's general practitioner to assist with the provision of palliative care.

Although it was reassuring to note that all staff members were involved in providing palliative care, no indications were given that these staff members were adequately trained in the field of palliative care. Nothing further was mentioned about having regular team meetings to evaluate and reflect on complicated situations or provide meaningful support to each other as suggested in the literature.⁴⁹ This will provide opportunity for team members to make combined decisions about patient care and to learn from each other's expertise. It will also provide the opportunity to express work related feelings or discuss possible problems in the work place. Effective training and mentoring from experienced clinical care workers should also be encouraged to aid in developing professional competence within the team, as stated by Meier *et al.*⁵¹

5.8 Shortcomings in the current palliative care services

The participants were of the opinion that a number of shortcomings were present in their current palliative care services. According to them being the sole provider of palliative care does come at a price. The complex responsibilities and hard work associated with this activity can put a great deal of pressure on the treating oncologist and may eventually lead to burnout. Some participants also felt that the lack of palliative care could unnecessarily prolong anticancer treatment in an attempt to support patients till the very end. They further believed

that referring these patients to palliative care services such as their general practitioners or local hospices might cause some to feel abandoned by their oncologists. However, such experience of abandonment could be alleviated by the provision of better integrated palliative care with standard oncology care. This was shown in the study by Smith *et al.*²⁰

Further reasons for concern were that the current palliative care referral facilities were regarded by some participants as inadequate. In their view general practitioners and ward staff members lacked palliative care knowledge. According to other participants their local hospice services had problems such as poor communication structures, unavailability of beds as well as poor support. Interestingly enough only participants working in the northern suburbs of Cape Town had these complaints about their hospice service. This may warrant further investigation to determine possible reasons for this poor relationship and to develop recommendations for an improvement of the situation. As some participants consider hospice referrals as a crucial element in the management of patients with advanced disease, good relationships with the available hospice services are essential.

5.9 Recommendations to improve palliative care facilities currently available at treatment units

Numerous studies have shown the importance of the implementation of the palliative care team approach in the management of patients with advanced disease in a standard oncology practice. Not only does this approach improve patients' satisfaction with care and symptom control but it also provides the treating oncologist with much needed support.^{3,56,79,80,81}

Therefore, it was reassuring to learn that most participants recommended the provision of exclusive multidisciplinary palliative care services together with the employment of a palliative care specialist to assist in the management of patients with advanced disease. The availability of these services at the units will provide the oncologists with valuable additional time to concentrate on more oncological specific treatment and will ensure that patients experience an early smooth transition to palliative care. The notion that the palliative care consultants should act as leaders of these multidisciplinary teams was very important because it was evident through the interviews that leadership in this field was lacking. The palliative care specialist

would also enhance communication between team members which is necessary to promote cooperation within a multidisciplinary team, as was shown in the work of Junger *et al.*⁸²

The strong recommendation that the patients' general practitioners be utilised more when their disease becomes advanced was a positive notion. Most patients have a strong bond with their general practitioners and would benefit from their services in the comfort of their own home. The general practitioners could further assist the oncologists in the provision of palliative care, easing the latter's work load by controlling symptoms or helping with the administrative work associated with their care. Essentially these general practitioners should be trained in the field of palliative care as some of them were believed to be uncomfortable with the provision of such a service. Once again, good communication between participating general practitioners and oncologists would be an important factor in ensuring continuity of care. In addition, the early hospice referrals of patients with advanced disease, as recommended by some participants, could further assist the treating oncologists in the care of these patients. Early hospice referrals would ensure better symptom management as well as possible less hospital admissions. Continuity of care could further be enhanced by having regular meetings with hospice staff to discuss the patient's condition or address any workflow issues as suggested by some participants. Although resources for specialised palliative care facilities in South Africa are scarce, according to some responses, utilisation of these existing outside modalities is a step in the right direction.

Medical officers, nurse practitioners and oncological social workers were also mentioned to be essential elements in the current palliative care setup. As with hospice services and the patient's general practitioner, their permanent presence in the units provide additional support for the treating oncologist. The social workers' service was regarded as invaluable and was recommended to be utilised more often in cases of patient distress. The training of medical officers and physician extenders (oncology nurses who manage patients' symptoms and concerns under the supervision of an oncologist) in palliative care were again accentuated by the participants. This will ensure that these staff members will be more comfortable in dealing with all the complicated issues associated with the care of patients with advanced disease

which eventually improve the quality of care. The availability of guidelines pertaining to palliative care issues and symptom management at the units, as suggested, will further aid in staff training and will probably make palliative care more uniform.

5.10 Limitations of study

5.10.1 Limitations pertaining to the study population

The study focused only on oncologists practicing in private oncology units in various parts of Cape Town. This may limit transferability of the data to oncologists practicing elsewhere in South Africa. The fact that the researcher purposefully recruited his sample from participants working for the same company and at units in close proximity to his working unit may be regarded as selection bias. This may also have influenced the participants' responses as they might have been cautious not to show weakness or vulnerability. Working in the same company as the researcher could also have made the participants more obliged to enlist in the study, hence the high response rate. Furthermore, time constraints associated with the participants' working schedule together with interruptions experienced during some interviews could have caused rushed or inattentive responses. Unfortunately, some interviews had to be rescheduled due to difficult time constraints. Nevertheless, the participants did not at any time give the impression that they were rushed or negatively motivated. They were always very eager to participate and gave very good feedback on their experiences.

5.10.2 Relevancy of the data

Despite these limitations listed, the data gathered did contain valid information regarding the management of patients with advanced disease in the private sector of South Africa. Although the results might not be representative of other private oncology centers in South Africa, the researcher believes that, as the sample included oncologists from several age groups; from various fields of specialisation; of different degrees of experience and of both genders the results reflect the preference of a broad range of oncologists practicing in the private sector of South Africa.

5.11 Summary of findings

It was evident from the findings that the management of patients with advanced disease is a complicated and stressful part of the participants' work. It not only constitutes a major part of the participants' daily work programme but also contains major challenges such as difficult discussions regarding disease status and cessation of treatment; dealing with fear and anxieties of patients and their family members; the discussion of advance directives and the provision of palliative care, a field fairly unknown to the participants. If these challenges are not managed properly it can easily lead to oncologists' burnout and eventually affect quality of care. Current shortcomings have been identified and recommendations have been made by the participants to successfully overcome these challenges and to improve the current palliative care services at their treating units. By adhering to these recommendations patient care and oncologists self care could eventually be improved. Further recommendations made by the researcher will be discussed in the final chapter below.

CHAPTER 6: Conclusion and recommendations

6.1 Conclusion

The management of cancer patients whose disease has become resistant to anticancer treatment is a complicated part of every oncologist's career. The aim of this study was to evaluate this particular practice of oncologists working in the private sector in Cape Town, South Africa, and to identify the needs associated with such management. It was evident from the data that the participants perceived this component of their work as challenging, filled with difficult problems which caused fair amount of stress. These challenges included, amongst others, the dealing with young terminally ill patients; with certain patients with advanced disease with whom a relationship was formed and to whom they became attached to; with the external pressures exerted by family members and with the difficult time constraints associated with the management of these patients.

Adding to these stressors are all the complicated issues associated with the difficult discussion which the oncologists must have with their patients when their disease becomes incurable. Most participants reported that they manage this discussion fairly well in an open and honest way. They provide comprehensive information regarding disease prognosis, treatment toxicities and efficacies with the aid of special investigations reports. They also try to incorporate discussions regarding palliative care treatment options in a sensitive way to ease the transition from curative to supportive care. Some support is however needed to overcome communication hurdles associated with these discussions. These hurdles include the management of patients in denial; surmounting feelings of failure; dealing with the emotional outbursts, fears and anxieties of patients and their family members and with the difficult time constraints associated with these discussions.

Further support is necessary to aid the treating oncologist in his complicated decision on whether anticancer treatment should be continued. This decision usually follows on the difficult discussion regarding the advanced state of a patient's disease. Reasons given for stopping anticancer treatment included disease resistance, poor patient tolerability and performance status, patient preference and insufficient funding by medical aid schemes. Guidance regarding

the patient's fitness for treatment and support to overcome pressures exerted by patients and their family members are necessary to aid the treating oncologist to prescribe appropriate anticancer treatment, especially in the private sector where numerous treatment options are available. The value of involving a multidisciplinary team to assist the treating oncologists during this arduous discussions and treatment decisions was also emphasised.

Advance directives play an important role in the management of patients with advanced disease. It ensures that patients' wishes regarding future care and treatment options are respected when they are not capable to decide for themselves. However, this particular practice is neglected by the participating oncologists. Reasons for this neglect include difficult time constraints and the unwillingness of patients to engage in such a discussion in fear of acknowledging the advanced status of their disease. Most participants felt that it implied that patients with advanced disease are not in favour of active resuscitation. Therefore, guidance regarding the aims and development of advance directives is necessary to promote this practice and to ensure that patients benefit from the advantages that are associated therewith. These advantages include frequent communication opportunities to discuss the patient's disease process, assurance that fears and anxieties are addressed and the timely discussion of the implementation of palliative care support services. It further prevents unnecessary stress and anxiety in instances where a patient becomes unresponsive to anticancer treatment and when a decision regarding further active management needs to be taken. Eventually, unnecessary invasive procedures, of which the outcome is often expected to be futile, will be prevented.

The current palliative care services at the different treatment units were also investigated. It was found that no formal palliative care team exists in any of the treatment units. Patients with advanced disease are managed by involving a team consisting of the staff present at the treatment units. These staff members include the oncologists, medical officers, physician extenders, chemotherapy sisters, radiographers, the oncology social worker and administrative staff who interact with the patients on a daily basis. External modalities such as hospice services and the patients' general practitioners are also utilised to provide palliative care and support.

However, shortcomings were identified within these particular structures. No real leadership existed within the treating team and regular team meetings for case discussions and support were not performed. The team also lacked the presence of members of other specialties who can make invaluable contributions to the care of these patients. Such team members may include a palliative care physician, psychologist, spiritual advisor, dietician, physiotherapist and a lymphoedema specialist, to name but a few. The lack of training in palliative care of the current members of these teams was also identified.

The study provided clear evidence of the participating oncologists' general lack of knowledge of and, hence, their need of formal training in palliative care. This can affect their attitude towards palliative care and may influence the quality of the care they are providing.

Problems with the external services involved with palliative care also emerged. These problems include poor relationship with the local hospice services at some units due to poor communication and the lack of available beds and support. The inability of general practitioners to provide adequate palliative care, mainly due to a lack of training, also came to the fore. Consequently, some oncologists were reluctant to refer patients to these services. Patients are also likely to experience feelings of abandonment when they are referred to these services for palliative care. As a result some treating oncologists are, in many instances, the sole provider of palliative care, which may add to additional stress. Their lack of knowledge of palliative care and lack of formal training in palliative care means that they are ill-equipped to take on the role of sole palliative care provider.

All these above mentioned stressors experienced during the management of patients whose disease has become incurable did have a significant influence on the participants' physical and emotional well being. Some participants' daily work and family life were markedly affected. A strong belief prevailed that some of the participants were actually suffering from burnout due to the presence of associated symptoms such as emotional exhaustion and frustration. Although most participants had some form of strategy to overcome burnout at the workplace, little support was given by their employers to ease their workload. Therefore, as a consequence of their continuous intensive involvement with patients with advanced disease, the treating

oncologists need support to identify, manage and prevent burnout. Not only will such support improve the oncologists' emotional wellbeing but it will also improve the quality of care rendered.

The holistic management of patients with advanced disease by their oncologists in the private sector of South Africa is a field which has, as yet, not been well researched. The researcher's study succeeded in its aim and objectives by providing a comprehensive description of the important aspects of the treating oncologist's management of patients suffering from incurable cancer in the private sector of Cape Town in South Africa. These identified topics represent the salient aspects commonly associated with this particular field. Identified needs of the oncologists associated with this field were also described. A number of recommendations to address the needs mentioned are given and will be discussed below.

6.2 Recommendations

It was evident from the findings that the participants lacked knowledge and proper training in the field of palliative care. This could be a cause for their negative attitude towards palliative care which constitutes a major part of their daily work programme. Further training in the field of palliative care is therefore necessary to improve their skills in and change their attitude towards this field. Currently, a part time correspondence diploma in the field of palliative care is presented by the University of Cape Town which is aimed at the provision of basic knowledge and skills in palliative care. It is recommended that GVI Oncology both encourage and create the opportunity for oncologists and other relevant staff in their employ to undergo this course. To maintain their acquired skills and knowledge, the personnel involved in palliative care should further be provided with the opportunity to regularly attend seminars and workshops in this field.

This study has shown that the difficult discussion between oncologist and patient when the patient's disease has become incurable and the decision whether anticancer treatment should be stopped has become unavoidable, is an extremely challenging part of any oncologist's work. The management of such a discussion is, in the majority of the cases, solely based on the perceptiveness and understanding of the treating oncologist, which is the product of years of

experience. Therefore, to ensure that such discussions be conducted with minimum distress for both oncologist and patient, the availability at all oncology units of suitable guidelines on the directing and management of this very important oncologist-patient interaction is essential. These guidelines should advise on aspects such as the timing of the discussion; breaking bad news to the patient and addressing fears and needs of the patient; the prescription of palliative chemotherapy and the determination whether the patient is fit for such chemotherapy; the discussion of palliative care referrals and follow up treatment plans; the involvement of social workers and family members; and the arrangement of follow-up discussions.

It has further been shown that the discussion of advance directives with and the development of such directives for patients have real advantages for the management of terminally ill patients. Therefore, this practice should be promoted amongst oncologists. Again, guidelines should be available at treating units to direct the oncologists through the communication process with their patients regarding this delicate matter. It would further be beneficial if leaflets providing information pertaining to the purpose and contents of advance directives could be presented to patients and their family members. In the preceding two paragraphs reference is made to the need for the development of guidelines for oncologist-patient communication regarding the nature of treatment after it has become clear that the patient's cancer has become incurable and for the development of advance directives. It is recommended that one set of guidelines on every one of these two subjects should be developed for GVI Oncology as a whole. It is further recommended that a staff member should be made responsible for this task and that the guidelines be developed through a transparent process of workshopping.

It clearly emerged in the course of this study that the most effective palliative care is provided at institutions where a multidisciplinary approach is followed which is coordinated through the activities of a formally constituted multidisciplinary team under the leadership of a dedicated palliative care consultant. It is therefore recommended that GVI Oncology seriously consider the establishment of such teams at its treatment units. The formation of teams of this nature will not only enhance quality of palliative care but will also serve to ease to a considerable

extent the pressure currently exerted on treating oncologists. It needs to be kept in mind that the creation of palliative care teams could be effected without major staffing implications. All treatment units visited already have nuclei of relevant professionals whose activities could, through a slight adaptation in management, be molded to contribute effectively to the provision of multidisciplinary palliative care.

Neither would it be necessary to newly appoint a dedicated palliative care consultant. A currently employed medical officer could, through experience and part time and in-service training, be prepared for the function of assisting the oncologists in the management of palliative care issues such as symptom control and psycho-social and spiritual support of the patients and their family members. The palliative care physician can further assist the treating oncologists by dealing with additional matters associated with the provision of palliative care. These matters may include completion of referral forms to different treatment modalities such as hospice services and medical referrals, the compilation of palliative care guidelines to assist in the provision of palliative care at the treatment units, the writing of motivations to medical aid schemes for healthcare at home or medication and equipment associated with palliative care, the completion of insurance forms and benefits claims of patients and the handling of correspondence with referring specialists and general practitioners. In addition the palliative care physician can negotiate more effectively with medical aid schemes the provision of enhanced benefits for palliative care services and can promote palliative care training and awareness amongst fellow staff members as well as amongst external treatment modalities.

During this study burnout has come to the fore as a fairly common phenomenon amongst oncologists. Despite its prevalence conspicuously little was done by the oncologists' employing company to provide support to enable the oncologists to cope with the problem of burnout. Therefore, it is recommended that the oncologists should be made aware of and tested for the warning signs and symptoms of burnout on a regular basis. Formal counseling services provided by independent counselors should be made available to the oncologists. Provision should further be made for regular staff meetings for debriefing and support. These meetings would provide the opportunity to discuss work related issues and difficult cases which, in turn, would

enable mutual advice and support between team members. Work experiences, both emotional and uplifting, should also be shared amongst staff members during these meetings to promote a sense of well being. Opportunity should be created to delegate work to share the load in order to alleviate difficult time constraints. Training in palliative care would increase the oncologists' competence and confidence in managing patients with advanced cancer and this would mitigate against burn out. Other identified training needs may be addressed to assist oncologists in their work.

It was evident throughout this study that managing patients whose disease has become resistant to anticancer treatment was perceived as a daunting task filled with complicated challenges. By implementing the recommendations above, this negative perception of the participants could be changed to a more positive outlook due to the development of coping skills and the provision of needed support. Further improvement of palliative care services at these treatment units will ensure that a high quality of care is rendered to patients which will send out a message of compassion and care. This will reflect positively on the company's image and may improve their client base. Oncologists who are willing to grasp palliative care and improve their knowledge and usage thereof may find that they will reap the rewards that are associated with this field, as stated by Twycross. These rewards include achieving symptom relief and rendering psychosocial support, gaining benefits from working in a supportive team, practicing thorough medicine, gaining inspiration and joy from interacting with patients and their family members and experiencing personal growth within the challenges of working with patients with advanced disease.¹³

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APPENDICES

A: Letter requesting permission to conduct research at research site

Attention: Head of clinical services

GVI Oncology
14 Mispel Road
Bellville
Cape Town
7500

Dear Doctor.....

Date

REQUEST TO PERFORM A QUALITATIVE RESEARCH STUDY AT GVI ONCOLOGY

I am hereby requesting permission to perform research, which forms part of my studies for a master's degree in palliative care, at your treatment units in the Western Cape.

The study is a qualitative, cross-sectional study in which private oncologists working for GVI Oncology will be interviewed to evaluate their current practice and identify needs when dealing with patients that are not responding to anticancer treatment anymore.

Fifteen oncologists currently working in the Vincent Pallotti, Rondebosch, Panorama, Cape Gate and Vergelegen units will be requested to participate in the study. Each oncologist will be approached by email and his/her written consent will be obtained prior to commencement of the study.

A report on the findings of the study will be sent to you and presentations to GVI staff will be provided by arrangement.

I look forward to performing my study at your site and will be fixing the date of launch once I have full ethical approval.

Please do not hesitate to call me should you have any questions or queries with regards to this study

Yours sincerely

Dr JC Grove
(Oncology Medical Officer)

Tel: 0861999914 (Rondebosch unit)

Email: jan-chris.grove@cancercare.co.za

B: Information sheet for oncologists participating in study

Dear Doctor

Date

Thank you very much for your willingness to devote some time to read this information sheet about my prospective study. I recently enlisted for my master's degree in palliative medicine at the University of Cape Town. Amongst others, the course includes a research dissertation that needs to be completed within the next two years. I would appreciate it if you would consider participating in my study that will be explained as follows.

Background and aim of study:

Patients with advanced cancer who do not respond to anticancer treatment represent major challenges for their treating oncologist. This study aims to investigate the current practices of private oncologists in the management of patients whose disease does not respond to anticancer treatment and to identify support needs. If you consent to take part in the study, I will contact you to confirm an appropriate time for an interview that will last approximately 30-45 minutes.

The interview will be digitally recorded and your identity will be kept anonymous. You are welcome to terminate the interview at any time. You will receive feedback in the form of a report on conclusion of the study.

Questions regarding the study:

Please do not hesitate to contact me telephonically or by email should you have further questions regarding the above mentioned study. If you are concerned about any ethical issues, please contact Mrs Lameez Emjedi of the Faculty of Health Sciences HREC, E 52, Room 24, Old Main Building, Groote Schuur Hospital, Observatory at telephone 021 406 6338.

Kind regards

Dr JC Grove

(Oncology Medical Officer)

Tel: 0861999914 (Rondebosch unit)

Email: jan-chris.grove@cancercare.co.za

C: Topic guide for interview

- General starting question:
 - What is your experience with managing patients whose cancer is no longer responding to oncology treatment?
- Communication skills of the oncologists:
 - Describe how you would communicate to your patient that his/her disease is not responding to anti-cancer treatment anymore and that treatment should be stopped.
 - Explore: Difficulties of conversations
 - Who is involved during consultation(family, caregivers)
 - What information is given to the patient and his/her family
- Factors influencing treatment decisions:
 - Describe the factors that will influence your decision to stop anti-cancer treatment
 - Explore: The influence of family members on decision
 - The influence of the patient
 - Difficult demands of the private sector
- Use of advance directives:
 - What are your views on discussing and using advance directives if a patient's disease is not responding to anti cancer treatment.
 - Explore: The views of the patient and family.
 - The advantages of advance directives.
 - Difficulties discussing it with family members and patient
 - Does this discussion result in an advanced care plan?
- The palliative care team approach:
 - Describe your palliative care team/facility present at your unit.

- Explore: Oncologist's understanding of palliative care.
 - The importance/role of palliative care in the private sector.
 - When is it appropriate to refer patients for palliative care?

- Burnout of the oncologist and necessary support:
 - Describe how the management of patients with incurable disease affects you emotionally and physically.
 - Explore: Strategies to deal with stress
 - Support systems in place for oncologists
 - Recommendations to counter burnout

- Recommendations to improve palliative care setup at treatment units

D: Permission from the research committee of GVI Oncology to perform the study at the requested treating units

Dear Jan Chris

I am copying DR Gouws comment in this mail for inspiration to you, perhaps this could be your Doctorate !!!!

You have permission to continue and please keep us posted

Warm Regards

Linda Greeff

For the Research committee

“I think it is an important piece of research, I would be happy to have sponsored him to interview all Oncologists in RSA, as I believe at least it will make them take note and hopefully acknowledge that there is a problem in dealing with this important issue. I accept it is beyond the scope of his research.

Maybe an electronic version once he has identified his initial findings may still be worthwhile to get the rest to think about what they do. To my mind it is simply easier to offer another line than have that exceptionally difficult conversation and have to deal with the consequences of not treating, maybe the problem is lack of support to effectively deal with those issues.”

Leon

E: Consent form for interviews

Consent form for interview

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

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

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 _____

F: Ethics approval letter

UNIVERSITY OF CAPE TOWN



Health Sciences Faculty
Human Research Ethics Committee
Room E52-24 Grootte Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6338 • Facsimile [021] 406 6411
e-mail: shuretta.thomas@uct.ac.za

15 June 2012

HREC REF: 206/2012

Dr J Grove
c/o Dr L Gwyther
Public Health & Family Medicine

Dear Dr Grove

PROJECT TITLE: AN EVALUATION OF CURRENT PRACTICE AND IDENTIFIED NEEDS OF ONCOLOGISTS WORKING IN A PRIVATE ONCOLOGY CLINIC IN SOUTH AFRICA, MANAGING PATIENTS WITH SOLID TUMOURS WHOSE DISEASE DOES NOT RESPOND TO ANTICANCER TREATMENT

Thank you for responding to the issues raised by the Faculty of Health Sciences Human Research Ethics Committee in your letter received 15th June 2012.

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

Approval is granted for one year till the 30th June 2013

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: www.health.uct.ac.za/research/humanethics/forms)

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

Please quote the HREC. REF in all your correspondence.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, HSF HUMAN ETHICS

Federal Wide Assurance Number: FWA00001637.

Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.

The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

s.thomas