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DEPARTMENT OF SOCIAL DEVELOPMENT

**DYING OF CANCER – IS IT THE PROCESS OR THE PLACE THAT
CONTRIBUTES TO A GOOD DEATH?**

A dissertation submitted in fulfilment of the requirements for the award of the

Degree of Masters in Social Science (Social Work)

By

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March 2012

Plagiarism Declaration

This work has not been submitted in any form as part of, or as a whole for any other degree.

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Signed:

Clare L. Manicom

Date:

31 March 2012

Rondebosch, Cape Town

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ABSTRACT

This Quantitative Study undertook to investigate what family members or caregivers of deceased patients from a private oncology unit in Cape Town experienced during the last week of that patient's life. The social expectation or conventionally held belief that Good Death is only attainable at home was challenged, with findings indicating that it is possible to achieve a Good Death in a hospital setting.

The questions posed in the study included an examination of where patients died, how family members experienced that death, what factors they believed contribute towards a Good Death, and finally, how many family members considered the death to be a Good Death.

Existing literature, particularly around Palliative Care in Oncology, Informal Carers and the concept of a Good Death was explored. A postal questionnaire was mailed to next of kin of patients who had died either at home or under their oncologist's care in an acute hospital ward, during a limited time period. Fifty eight respondents provided information about preparation for the patient's death, aspects of support and care that were present or absent, and an overview of what they believed to be a Good Death. Basic demographic data was collected using tick boxes followed by Likert-scales for a set of given statements. The questionnaire concluded with open questions allowing for free text response to direct questions posed to respondents. Information was summarised using descriptive statistics, along with a summary of content to obtain an overall view of the open questions.

Findings indicated that most of the respondents experienced death at home of the patient, with the majority of them being spouses or life partners of the deceased, as well as being the main carer for the dying patient. The study found that most patients who were admitted to the hospital for their end-of-life care did not have additional assistance from paid-for help in their own homes. By contrast, half of the patients who died in a home environment had additional paid assistance at home, which may have enabled them to remain at home until death.

The experiences of witnessing the death of a person with advanced cancer were described variously, with some respondents finding it extremely difficult while others recorded a sense of satisfaction or peace. Respondents listed pain control, a peaceful death and the presence of loved ones at the time of death most commonly as components of a Good Death. More than half of all of the respondents agreed that the death they had been involved with was a Good Death.

In order to better support the dying patient and family members, the study recommends that discussions regarding possible place of care and place of death be encouraged. Talking about individual preferences can ensure that patient autonomy is upheld should the patient be unable to make decisions. Recommendations for future action include improved support and care for the Informal Carers, and better preparation of oncology teams for the palliative care of patients with advanced cancer.

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University of Cape Town

CHAPTER ONE

Problem Formulation

1.1. Introduction

This study will investigate whether an adult dying of cancer can experience a Good Death in an acute care hospital. This investigation will challenge the widely held belief that it is better to die in one's own bed at home than elsewhere. The researcher plans to determine that it is in fact the process of the dying, and how that is experienced, that enables the perception of a Good Death, rather than the physical location of the actual death.

The first chapter of the study provides an introduction to the topic of private cancer care in the South African context, with particular attention to end-of-life care, which is the focus for the remainder of this study. The rationale for the study is followed by the statement of the Research Topic, the framing of the research questions and the setting of the research objectives and hypotheses. This is followed by a brief clarification of concepts that will be referred to and is discussed elsewhere in the study. Various ethical considerations are presented and an outline of the methodology for this piece of research is provided. The chapter ends with an overview of the structure of the dissertation followed by some concluding remarks.

1.2. Background to the problem

The term "cancer" refers to a group of illnesses that occur in humans and other animals, and describes a bizarre and rapid growth of cells associated with an organ or part of the body, often resulting in a tumour. The rate of growth and speed of possible spread of these malignant cells through the body determines how aggressive that cancer is and ultimately what the outcome will be for the individual patient. Cancer is also known to be a condition that is more commonly encountered in older people, with the result that the incidence rates for many cancers is higher in the older population (Parkin, Bray, Ferlay and Pisani, 2005).

Some cancers manifest for no apparent reason in individuals while certain cancers are known to have definite and proven links to lifestyle. Approximately a third of adult cancers diagnosed in the world today are believed to be preventable (Rosenthal, 2001) and many of these have close associations with the Western lifestyle that currently includes smoking behaviours, increasing obesity, lack of exercise, an excess intake of fats and sugars, and alcohol consumption (Jemal, Bray, Center, Ferlay, Ward and Forman, 2011). Sun exposure, certain environmental pollutants and certain sexually transmitted viruses can also contribute to the development of cancer in adults (Rosenthal, 2001).

However, improved screening for cancer and earlier detection of malignant cells, together with improvements in treatment techniques and an increased array of treatment options have all played a role in assisting the global overall survival rate for cancer, as a group of illnesses, to improve (Rosenthal, 2001). The survival rates for cancer are known to be higher in developed countries (Parkin et al, 2005; Jemal et al, 2011), where health care and resources are easier to access.

The term “oncology” refers then to the medical management of cancers and so includes various forms of assessments, interventions or treatments after a diagnosis of cancer has been made. In South Africa, oncologists are trained at the teaching hospitals and attain qualifications that enable them to prescribe various treatments for cancer, particularly those arising from solid organs in the body (eg lung, prostate, brain). In this country, specialists who work with blood malignancies such as the lymphomas and leukemias are called haematologists, and in the hospital where this study took place, the oncology and haematology practices function as separate entities.

Despite advances in the detection and early treatment of cancer, there remain many patients who cannot be cured of their illness altogether and who may die with cancer, or from it at some future point. Their lifespan may be extended by treatments, to the point that cancer is now considered a “chronic disease” in Western medical circles (Yach , Hawkes, Gould and Hofman: 2004),

meaning that it may require ongoing management in a similar way to chronic diabetes or hypertension. However, dying of cancer can be an uncertain path for both the patient and the family. The progression of the cancer through the body can happen gradually or rapidly, which makes accurate predictions and prognostication difficult for the oncologist involved in the patient's care (Edmonds and Rogers, 2003; Stone and Lund, 2007). Cancers that began in different sites (known as Primary Cancers) have different patterns and rates of spread, which again may be confusing for lay-people who do not know what to expect next in terms of physical symptoms (Edmonds and Rogers, 2003; Cain, Maclean and Sellick, 2004). There has been much work done on providing helpful information and meaningful support to the patient and family facing death from cancer (Eatmon, 2002; Mangan, Taylor, Yabroff, Fleming and Ingham, 2003; Glajchen, 2011). This can be achieved by conducting a thorough assessment of family and support system functioning (Glajchen, 2011) and by the medical team learning to include the family as part of the patient's overall health care team (Given, Given and Kozachik, 2001; Glajchen, 2011). This study aims to contribute to our understanding of the specific needs of carers and family members during this time.

It stands to reason that resources for assisting the dying person vary from place to place, and the African continent as a whole has major challenges, including the availability of essential medications (particularly morphine) in many areas; the difficulty of securing, training and paying staff to maintain a standard of care; and achieving an acceptance of Palliative Care in communities but with government support (Clark, Wright, Hunt and Lynch, 2007).

There has been limited research into place of death of people with cancer on the African continent (Hosking, Whiting, Braithwaite, Fox, Boshoff and Robbins, 2000; Kikule, 2003; Lazenby, Ma, Moffat, Funk, Knobf and McCorckle, 2010). This may be as a result of there being inadequate statistics as few African countries have active, accurate incidence and mortality figures on cancer (Parkin, Sitas, Chirenje, Stein, Abratt & Wabinga, 2008). Information about the place and circumstances of deaths in Africa is sparse (Setel, Macfarlane, Szreter, Mikkelsen, Jha and AbouZahr, 2007; Lazenby et al 2010). It is anticipated that with development of the Palliative Care movement and philosophy across Africa (Clark et al; 2007) there will be

increasing attention paid to manner of death, particularly the issues of pain control and symptom management (Gwyther, 2002).

Leading from the detail of manner and place of death, comes the concept of a Good Death which has been widely explored in Palliative Care literature (Steinhauser, Clipp, McNeilly, Christakis, McIntyre and Tulskey, 2000; Kellehear, 2007; Miyashita, Sanjo, Morita, Hirai and Uchitomi, 2007). Good Death is commonly accepted in contemporary Western Society as featuring the end of life with as few distressing symptoms and as much dignity as possible for the individual concerned (Kaufman, 2005). Historically, there were associations in the 1990's between euthanasia and Good Death, but these have been separated in more recent literature so that the concept of a Good Death stands alone, albeit that people may hold different individual interpretations of what constitutes a Good Death (Kehl, 2006). Contributing factors to familiar perceptions of a Good Death will form a major part of this research and will be discussed in greater depth in Chapter Two.

In Cape Town there are three academic hospitals providing oncology services (Groote Schuur Hospital, Tygerberg Hospital and the Red Cross Children's Hospital), and there are several private oncology practices. All of these facilities are well placed to deliver treatment and provide a surveillance service to survivors of cancer. While they also offer services to those whose cancer has returned, none is able to provide long-term, in-patient care for the frail patient with advanced cancer. The researcher has worked at a private oncology unit, which is a part of the Gouws en Vernote (GVI) Oncology group and was based at a private acute-care hospital for over ten years. During this time, her work included guiding and supporting the carers of the dying patient, often while the patient was hospitalised.

There are many limitations and draw-backs to dying in a busy hospital ward (Edmonds and Rogers, 2003; Costello, 2006) such as the lack of privacy in shared rooms, the bustle and noise of hospital routines. From experience, family members and patients may comment on a sense of anonymity in hospital, where there may not be the resources to provide individualised, personal care to every patient. Equally there exist several good reasons for patients to be cared for in

the dying process in a hospital rather than at home, which would include the more immediate access to medication and medical advice; the use of equipment which may be difficult to have in place at home (for example a hospital bed); and the presence of more helpers than at home for aspects of care such as lifting and turning (Wheatley and Baker, 2007). The question that has arisen over time in the researcher's mind, based on the privilege and challenge of witnessing death in hospital, and hearing accounts of death at home, is simple: Are there times that death in hospital is better than death at home? Conversely, is it always better to die at home? From this has gradually come the notion that, for many patients and family, it is not the "being dead" that matters, but it is the journey towards death that is potentially frightening and unfamiliar.

In this study, the hospital where patients were cared for by their oncologist was the Constantiaberg Medi-Clinic, which is in Plumstead in the southern suburbs of Cape Town. This hospital is part of a privately owned hospital group, meaning that patients have to pay for admission and care. Those with medical aid (or medical insurance) may have access to care depending on the benefits of their particular medical scheme, whereas those without medical aid would have to pay a deposit on admission, and would then be required to make payments to cover their care during their stay. Patients of GVI Oncology (Gouws en Vernote Ingelyf which translates to Gouws and Partners Incorporated) may be offered symptom control in hospital which becomes end-of-life or terminal care, but there have to be clear medical grounds for hospital admission in order for medical aids to authorise payment of such admissions.

The GVI Oncology Group of practices was founded in 1990 in the Western Cape and now has nine treatment practices, most of which are in the coastal provinces of South Africa, with Constantiaberg being the oldest predominantly English-speaking practice in Cape Town, having been established in the late 1990's. Each practice within the group serves a different geographical area, and hence each has differing socio-economic profiles for their patients. The practice at Constantiaberg, during the time of the study, had three oncologists working exclusively at that practice, and offered treatments to patients on site, with the convenience of there being a specific hospital ward available for admissions if required. The only other predominantly English-speaking practice in Cape Town was established in the mid 2000's, and

relied on several different wards for patient admissions when necessary, with the result that style of care varied according to the management style of a particular ward in that hospital.

GVI Oncology staff are appointed, trained and managed through a Head Office structure ensuring that knowledge and skills of individuals are of a consistently high standard. Each practice has a multi-disciplinary team of medical professionals employed to provide whole patient care, including two or more oncologists, medical reception and administration staff, chemotherapy nursing sisters, nursing support staff, radiation therapists, and an oncology social worker. Each unit has access to its own medical physicist and many practices have medical officers on site as well to assist the oncologists. The practices are owned by a group of oncologists and typically include chemotherapy and radiation treatment facilities in buildings nearby to private hospitals where patients can be admitted if necessary. As the practices are independent entities, patients admitted to the hospital wards are cared for by hospital staff, not by GVI Oncology staff although the oncologists and other team members regularly visit and support patients and families in the ward setting. (www.cancercare.co.za)

The oncology social workers employed by GVI Oncology are required to support the psycho-social needs of patients and families in various forms and at all stages of the patient's association with the practice. The patient is not charged for this service, with salary and associated costs being covered by the practice. The oncology social worker may occasionally meet a patient early on in their illness (sometimes before initial surgery) and will work within the patient-system on cancer-related matters for as long as necessary, which may include support during dying and bereavement work with the family. Social work interventions vary greatly from individual to couples or family work, including psycho-therapeutic interventions, crisis intervention, psycho-education, practical assistance such as discharge planning and so on (Monroe, 2004). End-of-life care for the patient and family can be particularly involved, with the social worker needing to balance emotional support with the practical and informational needs of the patient's family (Monroe, 2004; Glajchen, 2011).

Families and loved ones may assume the role of Informal Carers for the dying patient with little preparation for this role. Physical, emotional and spiritual care for the person with incurable

cancer often falls under the jurisdiction of the local Hospice organisation, which is well developed, although stretched, in the Cape Town area (Hickman, 2008). There is a government-funded Home Based Carers system in place which provides limited care for chronically ill and frail people in their homes, generally in the less-affluent areas (Harding and Higginson, 2005). These Carers are trained in basic home care, primarily for people with end-stage Acquired Immune Deficiency Syndrome (AIDS). Advanced AIDS features many different symptoms and challenges that need to be managed differently from end-stage cancer, meaning that specific care needs for people with terminal cancer may not be familiar to Home Based Carers. The Carers are poorly paid through a government stipend, and often work under difficult conditions.

From the above, it is apparent then that the burden for caring for the dying from cancer in South Africa falls onto the community. Most families and friends are ill-equipped physically and in terms of person-power to undertake this task, requiring considerable support and on-the-job instruction or advice. Frequently these informal carers feel insecure and unsure about how to care for their dying which is often a full time commitment (Morris and Thomas, 2001; Soothill, Morris, Thomas, Harman, Francis and McIlmurray, 2003). Much has been written about the growing role and importance of informal carers around the world, although more developed countries have better financial and practical support systems in place for these essential members of the patient's health care team (Murray, Grant, Grant and Kendall, 2003; Aoun, Kristjanson, Currow and Hudson, 2005; Harding and Higginson, 2005). Compounding this scenario of uncertainty, carer-fatigue and the management of terminal cancer is the real possibility of a sudden change in the patient's condition as they near death. This change can be sudden and distressing for both the patient and the carer. It is not uncommon for families to bring the deteriorating patient to an acute care hospital at this point resulting in admission to help settle the patient's distressing symptoms, with death following within a few days (Manicom, 2011). While a patient in this situation may die in hospital, it is possible that this facility was preferred as a place of death by the family and possibly the patient themselves.

1.3. Rationale

Although much has been written about palliative cancer care, the place of death of adults with cancer, and the development of the concept of Good Death, most of the literature has originated

from North America and Europe. In Scandinavia where community health care services are advanced and sophisticated, with good support for family members, a high number of patients are cared for in their homes until death (Carlsson and Rollison, 2003). Concern has been expressed by other authors that the trend for dying in hospital is increasing in England (Davies, Linklater, Jack, Clark and Møller, 2006; Gomes and Higginson, 2008), which has implications for the national health budget in that country.

In South Africa, this information is lacking and has not been recorded on a national or regional basis. Cancer itself is not a major cause of death in this country with HIV/AIDS being the biggest cause of deaths in South Africa, followed by homicide and violence when viewed across both genders (Bradshaw, Groenewald, Laubscher, Nannan, Nojilana, Norman, Pieterse, Schneider, Bourne, Timmaeus, Dorrington and Johnson, 2003). These authors found that cancer of the cervix was the 15th largest contributor to deaths amongst South African females, with cancer overall causing 7.5% of all deaths in this country (Bradshaw et al, 2003). The lack of a National Cancer Registry makes it difficult to know with any certainty how many new diagnoses are made in a year, or how many people in total die of cancer in South Africa annually (Mqoqi, Kellett, Sitas and Jula, 2004; Parkin et al, 2008; Manicom, 2010).

The researcher's previous work reveals that 42% of patients from the oncology unit in question died at home with an additional 33% dying under the oncologist's care in hospital during the three year period 2006 – 2008 (Manicom, 2011). This previous work does not record the quality of the dying process and does not include any observations from family members. The researcher is therefore of the opinion that the results from this study may provide new insights into the experiences, expectations and needs of patients and families within an urban context in South Africa.

This study will therefore contribute to academic knowledge by providing quantitative evidence of the observations of bereaved family members regarding the quality of the dying experience they witnessed. The study will also provide clinical insights for practitioners in terms of patient and family needs at end of life, especially when the patient is in hospital under the oncology team's care. These particular insights should lead to better patient care in the physical realm and

to improved emotional support for the dying and their carers. These findings are to be conveyed to nursing staff and hospital management, as well as to the oncology team involved with patients in the Constantiaberg Medi-Clinic. In addition, the recommendations from the study will be utilised in a professional setting to raise awareness of needs and rights of the dying within the GVI Oncology group of practices and potentially through the oncology community in South Africa by means of participation and presentations at local congresses. There will be verbal academic presentations of the findings and recommendations to multi-disciplinary teams within GVI Oncology. The findings of this study will be presented in different formats to staff and the Executive Management Committee at GVI Oncology – both in full and as a summary for easier reference.

It is hoped that findings from this study will lead to a more structured way of working with a patient dying of cancer and their family which would include:

- Renewed commitment to physical care that is appropriate in hospital – ideally improved symptom management, better focus on comfort of patient and family by all team members working with the patient
- Improved communication within the multi-disciplinary team and with the patient system – this would include verbal support, the discussion and recording of the patient’s wishes around care at end-of-life
- Potential lobbying of medical aids and funders for better Palliative Care provisions based on this research. Such lobbying could be done by the GVI Oncology group which regularly negotiates with medical aids and policy makers about cancer care in this country.

1.4. Research Topic

Dying of cancer – is it the process or the place that contributes to a good death?

1.5. Research Questions

- 1) Where did the patients from a private oncology unit die during the period 01 January 2008 – 31 October 2010?
- 2) How did the family members experience the patient’s death?
- 3) How would family members define a Good Death?
- 4) Do the family members consider this death to be a Good Death?

1.6. Research Objectives

- 1) To establish the place of death of patients from a private oncology unit in Cape Town in a two year period (01 January 2008 – 31 October 2010).
- 2) To record family members' experiences of the patient's death.
- 3) To list components the family members contribute to a Good Death.
- 4) To assess how many family members think the death they experienced was a Good Death.

1.7. Hypothesis formulation

At the foundation of a piece of research is the hypothesis which is a statement linking the relationship of one variable to another, with the requirement that the relationship can be measured or proved to exist or not (Brink, 2009; de Vos in de Vos et al, 2010).

The fundamental hypothesis in this study is that, contrary to common wisdom, a Good Death is achievable in hospital or at home.

To attach a hypothesis to each of the research objectives:

- 1) Most patients from the GVI Oncology Practice at Constantiaberg Medi-Clinic who died during the time frame 01 January 2008 to 31 October 2010 did so at home. This was tested by a review of statistics of where death occurred during the given time period.
- 2) The family members would report a variety of experiences and observations about the death of the patient. This hypothesis was tested in the responses to the postal questionnaire.
- 3) Family members would include pain and symptom management, a sense of peacefulness and readiness for the death as components of a Good Death. Responses to the postal questionnaire provided a list of words and phrases that addressed this hypothesis.
- 4) Regardless of the place of death, family members would rate the death they witnessed as being a Good Death. The fourth research objective stated above holds the hypothesis which underpins this study. The hypothesis is that Place of Death alone does not

determine whether a Good Death is experienced or not and is tested by the final question in the postal questionnaire.

1.8. Concept Clarification

Dying for the purposes of this study refers to the final few weeks of life, and includes not only the physical process of bodily death, but acknowledges the social, psychological and spiritual components of this process as well. Although there are varying psychological theories about the negotiation of the dying process, the common theme whichever way dying is viewed is of the permanent loss of that physical person, whether the dying is a gradual or a sudden event. There have been differing approaches to the defining of death – varying from perceiving death as a process to death as an event (Kehl, 2006). In the light of this, the researcher therefore will use the term ‘death’ to describe the moments immediately prior to and following the end of life.

Cancer is a broad term used to describe a group of medical conditions that feature the uncontrolled and bizarre growth of certain cells in the body. These cells originate from any organ or part of the body, and there may be a spread of the cells within the body (Rosenthal, 2001). The medical specialty devoted to the study of cancers is known as Oncology (Cape and Dobson, 1974).

A **family member** in this study refers to anyone who is considered by the patient, blood relatives or themselves as a family member of the patients. It is therefore a social term rather than a biological definition, indicating close emotional and social bonds between the patient and that person.

A **Good Death** refers to the satisfactory manner in which a person died, and is a subjective description as the experience of death is not measurable. Steinhauser and colleagues (2000) have defined a “Good Death” as comprising certain essential elements from the dying person’s point of view: pain and symptom control; clear decision making involving the patient as far as possible; preparation for death for patient and family members; a sense of completion at different levels (practical, economic, relational, spiritual); a belief in the dying person’s own contribution to others; affirmation as a whole person (Steinhauser et al, 2000).

The word **Place** is a noun that indicates a specific physical location or position that is regarded as a unit or single entity (Robinson, 1999).

Process is defined with several meanings including a series of changes, particularly naturally occurring ones (Robinson, 1999). By extension, the Process of Dying is a term used in this study to describe the experience of dying of cancer, so broadly will include the spiritual journey, the emotional and relationship aspects of leaving life, and the physical experiences at the end of life to the time of death itself.

1.9. Ethical Considerations

As a piece of academic research, this study is required to adhere to ethical standards that are sound academically and are consistent with ethics of the profession of social work. These are referred to as professional obligations by Clark-Carter (2010) who emphasises the importance of such observances throughout the research process – from planning, to the conduct of the investigator, to the eventual reporting of findings. Strydom in de Vos et al (2010) points out that there is a dual requirement in the field of Humanities to conduct research that is ethically responsible in terms of the subjects being studied, together with the essential foundation of a rigorous and honest scientific approach to research.

1.9.1 Informed consent

The principle of informed consent is crucial to ethical research and requires that potential subjects have all possible information about the study before they consent to participation (Strydom in de Vos et al, 2010). Subjects for this study were invited to participate by means of a letter that was posted to them by the researcher, explaining that their response to the letter and questionnaire was voluntary and would in no way prejudice any future interactions they may have with the GVI Oncology group of practices, or the researcher. The purpose of the study and questionnaire was outlined and the possible uses of the findings were mentioned. There was no payment or reward offered for completion of the questionnaire, and subjects were deemed to be voluntary participants by virtue of their returning the questionnaire.

1.9.2 Confidentiality

The participant's right to privacy, confidentiality and anonymity is central to ethical research and is highlighted as being a principle applicable to all subjects of research (Brink, 2009). The researcher emphasised in the letter of introduction that data has been gathered from the oncology practice's record, where the researcher was employed. Furthermore, subjects who choose to respond used a questionnaire that required only broadly general information about the deceased, with minimal identifying information about the respondent, namely gender, age, relationship to the deceased. This ensured that the respondents feel protected by anonymity, which can also be described as 'namelessness' (Brink, 2009). It has been suggested that respondents may provide more honest answers to questions when they believe their responses are anonymous (Clark-Carter, 2010). This study relied on the honest completion of the questionnaire in order to provide accurate insights.

1.9.3 Avoidance of harm

Strydom in de Vos et al (2010) highlights the possibility for subjects being harmed physically or emotionally in the process of the investigation. The study being undertaken did not involve any exposure to physical harm, but the potential for emotional distress existed as the participants were asked to recall circumstances around the death of a loved one. As a step towards preventing evoking emotional harm, the researcher selected as the study population people whose loss had been at least twelve months prior to responding to the questionnaire. This time delay was selected to allow the period of acute grief to pass, and has been shown by previous researchers to be an appropriate interval for respondents (Addington Hall and McPherson, 2001). Furthermore, recall for up to seven years post bereavement has been shown to be reliable (Krajnik, Szymanowska, Adamczyk, Kozaka, Skrzypski, Szostakiewicz, and Jassem, 2008). By making participation voluntary, the researcher allowed for non-participation without any repercussions for the subject, which reinforced the concept of "choice" that each person had to be a part of the study or not (Brink, 2009).

1.9.4 Debriefing and support for respondents

The medical ethical principle of Beneficence is evidenced in the offer of debriefing or support for participants in the current study (Brink, 2009). Supportive counselling for respondents, who

might have felt distressed or emotionally disturbed by the questionnaire and the memories evoked, was available to the respondents through the GVI Oncology group of practices. This service would assist respondents who experienced distress and acted as a mediator of possible unintended emotional harm that might have resulted from completing the questionnaire (Strydom in de Vos et al, 2010). The researcher's colleagues at corresponding units in the Cape Peninsula were asked to provide bereavement counselling or debriefing if the participants requested this in their response. The respondents were informed that the services of oncology social workers within the GVI Oncology group remain free of charge to patients and their immediate family or carers, throughout the illness and during bereavement, so there was no payment required for this counselling. This accessibility prevented the exclusion on a financial basis of people requiring psycho-social support.

1.9.5 Publication of findings

By presenting the findings of this study in a professional report, without any identifying information included, individual's rights to privacy will be respected (Strydom in de Vos et al, 2010). Full copies of this study will be submitted to the University of Cape Town in compliance with requirements for degree purposes. The GVI Oncology group will also be presented with a full copy for their records as the work directly relates to their operation. In terms of requirements from the Department of Social Development at the University of Cape Town, the researcher has undertaken to co-author an article for publication with her supervisor, based on this study.

1.10. Overview of the methodology used

This study uses a quantitative approach featuring Descriptive Research, with a postal questionnaire as the primary data collection tool. People identified as next-of-kin of the deceased patients in the targeted population were approached to participate on a voluntary and anonymous basis. The data gathered was analysed using descriptive statistics and is reported on alongside existing literature from researchers in this field. In addition to the statistics, use is made of content analysis of the responses to the two open-ended questions in the questionnaire.

1.11. Structure of the dissertation

This dissertation is presented in five chapters, followed by Appendices containing additional information to the text. The first chapter presents a background to the study and the problem formulation. The chapter following this contains a Literature Review which provides an insight into existing works, theories and offers general background to the study. Chapter Three describes the Methodology used in conducting and presenting this research. The following chapter on Findings and Discussion of Findings offers details of the information gathered in the study, and preliminary observations based on these. Chapter Five contains Conclusions and Recommendations, reviewing the work as a whole and summarising the results.

1.12. Conclusion

This chapter has provided a brief overview of the context in which the study takes place. Current concerns about care of the dying in the private health care sector were mentioned, and work done by other authors in different countries has been noted. Objectives for the study have been set together with their related hypotheses. Concepts to be addressed and explored in the study were defined. These were followed by a review of ethical considerations or challenges in undertaking the research, and potential limitations of this study were outlined. In order to understand the broader theoretical and philosophical approach towards caring for the dying cancer patient, a literature review follows in Chapter Two.

CHAPTER TWO

Literature Review

2.1 Introduction

Care for people dying of cancer and support for their families provides the focal point for this study. The care required by dying people extends beyond physical needs, and includes emotional, social and spiritual needs (Faull, 1998). Similarly, the needs of people with cancer are broader than medical interventions alone and require a psychosocial approach (Wells and Turney in Lauria, Clark, Hermann and Stearns, 2001) that includes attention to not only the emotional well-being of the patient, but social support and interventions for family (Christ in Holleb, Fink, and Murphy, 1991). The theoretical frameworks on which this research rest include the broad background of Psycho-Oncology which in turn overlaps with the principles of Palliative Care. Oncology social workers are medical social workers who have chosen to work in the specialised field of cancer care. Not all oncology social workers will be involved in Palliative Care, and visa versa, Palliative Care social workers are not all oncology social workers.

In studying the literature, the researcher has used the field of Psycho-Oncology as a foundation, including the work and the role of the social worker especially in end-of-life care. The field of Palliative Care provides a medical discipline on which care of the dying is based, and work from this field that includes psycho-social care is also provided. Literature focussing on the role of family members or significant others as Informal Caregivers is included as their involvement in caring for a person dying of cancer is often vital, and their particular needs may be unmet by medical teams working with the dying patient (Glajchen, 2004). Following this the researcher will examine what works have been produced addressing Place of Death as well as the concept of Good Death and how that has been described in the literature. Finally, in order to set this study fully in context, there is a discussion on past and present theories on grief and bereavement – the natural consequences of preparing for and reflecting on death.

Most of the material from which the researcher has drawn for this literature review is from North American, European and Australian authors. However, South African works have been specifically sourced and quoted to provide a local context as far as possible, and to provide

evidence of what work is being done in this country in the realm of Oncology and Palliative Care.

2.2 Theoretical Frameworks

As this study focuses on the needs, care and experiences of the dying cancer patient and family, it is important to obtain an overview of the field of Psycho-Oncology, followed by a more detailed examination of Palliative Care and aspects of end-of-life care.

2.2.1 Psycho-Oncology

Psycho-Oncology developed as a sub-specialty within the field of cancer care in the last 25 years of the twentieth century in the United States where it originated from consultation-liaison psychiatry in the mid 1970's (Holland, 2002). As a psychiatrist at the Memorial Sloan Kettering Cancer Centre in New York City, Jimmie Holland was an early pioneer in Psycho-Oncology and her review articles documenting the history of this developing field provide a useful background and introduction to Psycho-Oncology (Holland, 2002; Holland, 2003). Psychiatrists were initially consulted by oncologists to help manage the anxiety, depression and other psychiatric symptoms the people undergoing cancer treatment manifested, resulting in a focus on the psycho-pathology of patients during the acute phase of their illness, at a time where curative treatments for cancer were still being developed, so that cancer as a disease had a high mortality rate (Holland, 2002).

As medical interventions improved, cancer survival rates increased, together with social pressures for more open and honest discussions with patients, cancer care in the late sixties and early 1970's began to change. A major contributor to this change was the realisation of the importance for practitioners to disclose and discuss the diagnosis and treatment of the patient's cancer (Holland, 2002). Studies by psychiatrists and psychologists began to demonstrate the range of emotional responses to a cancer diagnosis and treatments, to the point that by 1975 there was sufficient interest and support for a national research conference in Psycho-Oncology to be held in Texas (Berard, 2002; Holland, 2002). Since then, Psycho-Oncology has extended beyond the realm of psychiatry and now embraces a variety of professional disciplines as well as (more recently) a broader range of supportive therapies such as pastoral care, rehabilitation specialists,

and certain complementary therapies (Holland and Gooen-Piels, 2000; Holland, 2002; Keller, Weis, Schumacher & Greissmeier, 2003).

Together with nurses, social workers were among the first professionals to offer psychological and social support to patients with cancer and their families (Holland, 2002) and Oncology Social Work was recognised as being a speciality within Medical Social Work in the United States during the 1980's (Fobair, Stearns, Christ, Dozier-Hall, Newman, Zabora, Hill Schnipper, Kennedy, Loscalzo, Stensland and Hedlund, 2009). Social workers are active in all aspects of cancer care, from diagnosis through to bereavement work with relatives of deceased patients, and in South Africa are employed in State hospitals and clinics, as well as in some privately-run oncology units (Manicom, 2010). In countries where health care systems are more developed, Oncology Social Workers may function in broader roles – from primary education in cancer prevention, to administrative and teaching responsibilities, to contributions towards developing and maintaining national cancer control plans (Fobair et al, 2009).

Essentially, Psycho-Oncology focuses on two aspects of cancer care, namely the observation of, and the implementation of interventions to assist with psychological responses of patients and families to cancer at all stages of the disease, and an exploration of factors impacting on cancer risk and survival profiles, including emotional, behavioural and social factors (Holland, 2003).

Most oncologists and treating professionals acknowledge that emotional and social disarray is to be anticipated as people are diagnosed with and treated for cancer (Fedorchuk, Mendiondo and Matar, 2003). From this follows the understanding that many emotional responses are normal and that people can be assisted in their coping by offering them access to social workers, psychologists, rehabilitation teams and pastoral counsellors (Zabora and Loscalzo, 2007). Aligned with incorporating psycho-social care into the general realm of oncology management, comes the truism that people will require support at all stages in their cancer illness (Christ in Holleb et al, 1991). For example, late side-effects of treatment and long term survivorship are increasingly being studied as treatments are more successful with longer survival rates (Fosså, Loge and Dahl, 2008). In addition to this there is a large body of information that continues to grow focusing on emotional and social consequences of cancer recurrence and possible repeat

treatments for advanced disease (Christ in Holleb, Fink and Murphy, 1991; Wells and Turney in Lauria, Clark, Hermann & Sterns, 2001; Schofield, Carey and Aranda, 2006). The field of medical management that seeks to relieve symptoms, and provide care in the face of progressive, incurable disease is known as Palliative Care (Faull, 1998). Psycho-Oncology in this arena has an understandably vital role to play (Tanchel, 2003).

2.2.2 Palliative Care

Concern about medical management and care for the dying was raised during the 1950's and was written about and challenged in academic papers into the 1960's (Clark, 2002). The discipline or field of Palliative Care (PC) therefore traces its origins back to the 1960's and 1970's (Bruera and Lawlor, 1998) when pioneering doctors such as Dame Cecily Saunders (who founded St Christopher's Hospice in London in 1967) and Dr Elisabeth Kübler-Ross began to explore the attitudes and difficulties of patients and staff, encouraging discussion between staff, and with patients themselves, about dying and choices that could be made regarding interventions or treatments (Hickman, 2008; Kübler-Ross, 1969).

The Medical Principles of Palliative Care require that interventions follow an evidence-based, rational and logical approach to the management of physical symptoms, with an emphasis on achieving quality of life for whatever time the patient has remaining (O'Neill and Fallon, 1997). These basic principles comprise: the anticipation of symptoms; evaluation and assessment of the patient's condition; explanation and information sharing with the patient; individualized treatment based on available information; re-evaluation of responses to the interventions together with supervision of procedures and medications; and ongoing attention to detail (Faull, 1998).

2.2.2.1 Defining Palliative Care

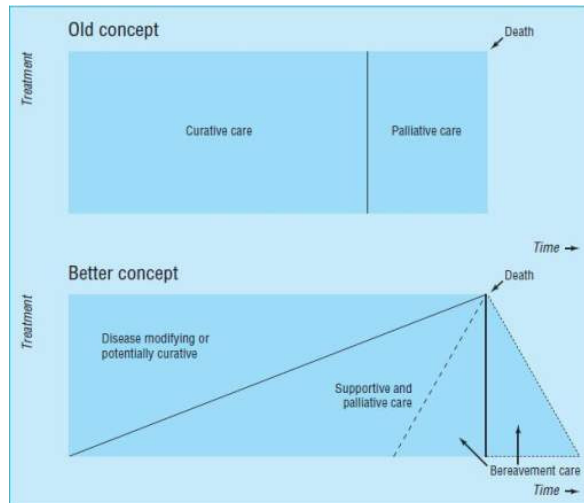
The World Health Organisation defined Palliative Care in 1996 and revised the definition in 2002, outlining it as being a specific approach that aims to improve the lives of patients who face a life-threatening illness, including cancer, and their families (Ahmedzai, Costa, Blengini, Bosch, Sanz-Ortiz, Ventafridda and Verhagen, 2004). The definition sets as a baseline the prevention of and relief from symptoms in various forms, and requires that psychosocial and spiritual needs be included in the care approach (Callaway and Ferris, 2007), underpinned by the teamwork of a

professional Palliative Care team (Twycross, 2003). Palliative Care is a patient-centred approach, accepting death while affirming life, requiring a partnership between the patient and carers, and focusing on healing rather than curing the patients' condition (Twycross, 2003).

The term has developed and assumed different meanings over the years, but essentially focuses on preventing where possible, or at least relieving suffering, alongside the intention to improve the quality of life for the patient (Pastrana, Jünger, Ostgathe, Elsner and Radbruch, 2008).

PC can be practised independently of Hospice or in-patient care and is not restricted to the diagnosis of cancer alone but may include other chronic conditions such as progressive muscular degenerative conditions, cardiac or renal failure and end stage AIDS (Foley, 2003; Murray, Kendall, Boyd and Sheikh, 2005; Clark, 2007). More recent texts and articles suggest that PC should be introduced at the beginning of care and be implemented alongside treatment for life limiting illnesses (Higginson and Costantini, 2008). This is illustrated in Figure One, which indicates how the introduction of PC at the point of diagnosis of a life threatening illness can provide continuous support to the point of death and beyond, into bereavement care (Lynn and Adamson, 2003). Older models of the introduction of PC presented an either/or situation, implying that once the aim of cure was no longer attainable, then only could PC be initiated, effectively in preparation for death. This is indicated by the vertical line in the top diagram in Figure One on the following page:

Figure One – The integration of Palliative Care from time of diagnosis



(Taken from Murray, Kendall, Boyd and Sheikh (2005), based on Lynn and Adamson (2003)).

2.2.2.2 The Palliative Care Team

One of the factors that distinguishes the Palliative Care approach from other medical disciplines is the concept of “team” that is central to providing care for the patient and the immediate family or carers (Schachter and Coyle, 1999). The medical team is extended beyond the limits of doctors and nurses to include mental health practitioners, social workers, religious and spiritual supporters, volunteers and at times additional therapists. This team is referred to as being “Interdisciplinary” (Schachter and Coyle, 1999; Crawford and Price, 2003) in that each discipline is seen to have a contribution to make, with leadership of the team being assumed according to the patient-specific task or goal at any particular time (Crawford and Price, 2003). The Interdisciplinary Team therefore is able to address varying needs of the patient and family with flexibility and with easy access to expertise from different team members (Crawford and Price, 2003), relying on strong principles of clear and open communication between team members, a common goal for care, clarity of roles within the team, flexibility and good collaboration and support between members throughout the caring process (Nelson-Becker and Ferrell, 2011). In the context of PC, the patient’s needs should remain the focus, ideally with the patient being the final decision-maker (Crawford and Price, 2003). This philosophical approach is in direct contrast to the traditional and more familiar model of health care, with the top-down,

paternalistic style of the doctor being the head of a medical team, assuming the leadership role and making decisions on behalf of the patient. While the Interdisciplinary Team concept is not without its challenges and difficulties at times, it presents the patient and Informal Carers with support and access that may have been less possible to achieve in more traditional medical setting.

2.2.2.3 Palliative Care and Ethics

One of the foundations on which the PC philosophy is based is the inclusion of the patient and, by extension the family, as part of the caring-team (Pastrana et al, 2008), upholding autonomy as opposed to paternalism in interactions with medical teams (Jeffrey, 1998). The respect accorded the patient as a partner in their own care upholds the individual's right to patient autonomy by including the patient in decision-making processes (Ahmedzai et al, 2008). This approach recognises the patient's right to know what was happening in their own bodies, supporting the ethical principles of self determination and beneficence (Davis, 2005; Duba and Magenta, 2008). Aspects of beneficence are most readily illustrated by a compassionate approach from professionals towards their patients and their support systems (Jeffrey, 1998). The necessity for beneficence is emphasised by Norval and Gwyther (2003) who stress the importance of professionals keeping abreast of academic and technological advances, explaining how current and up-to-date knowledge will enhance that professional person's ability to provide competent, evidence-based care.

The rights of dying people became increasingly championed as the acceptance of PC as a discipline developed and grew to the point that access to PC is now recognised by the World Health Organisation (WHO) as being a fundamental human right (Brennan, 2007; Gwyther, Brennan and Harding, 2009). In supporting this position, the WHO has additionally outlined recommendations for the provision of care to communities in differently-resourced countries (Brennan, 2007). PC services are in place in 115 out of 234 countries worldwide, including 16 African countries (Wright, Wood, Lynch and Clark, 2008).

In addition to the ethical principles of patient autonomy, and the ever-present medical principle of beneficence, there are the principles of non-maleficence and of justice that both have in PC

(Norval and Gwyther, 2003). The authors outline briefly some of the challenges that exist in South Africa in terms of access to resources, highlighting the issues of distributive, rights-based and legal justice – all of which have bearing on health care in this country (Norval and Gwyther, 2003).

2.2.2.4 Palliative Care in Africa

Globally, the need for PC is increasing as resource-rich countries face the challenge of ageing populations and the accompanying rise in age-related illnesses, and as the incidence of cancer and AIDS continues to increase in developing countries (Seale, 2000; Callaway and Ferris, 2007; Gomez Batiste and Paz, 2007). It is estimated that more than 30 million people worldwide require PC, although not all of them have access to it (Stjernswärd and Gómez-Batiste, 2008). In Africa, the need for PC tends to focus on AIDS and cancer as the major contributors to non-violent deaths, with approximately half a million deaths per year attributable to cancer (Harding and Higginson, 2005). Interest in, and support for PC in Africa has grown during the past twenty years, with not only funding, but operational and academic support being made available by donors and institutions in Europe and the United States (Clark et al, 2007; Di Sorbo, 2011). In Southern Africa, PC has developed in an attempt to meet the challenge of the many thousands of people facing end-stage AIDS (Ramsay, 2001; Harding and Higginson, 2005), with formal academic training in PC being available at the Makerere University College of Health Sciences in Uganda, and at the University of Cape Town in South Africa (Gwyther and Rawlinson, 2007; Ddungu, 2011). A review article by Gysels, Pell, Straus and Pool (2011) explores existing articles written about end-of-life care in sub-Saharan Africa, highlighting the focus on the AIDS in many of the works and suggesting that more work needs to be generated to explore other the care needs of people with other terminal illnesses such as cancer.

Gysels et al (2011) further suggest that the pattern of community and home based care in this region may be established but might no longer accurately reflect the preferences of the consumers, who are reported in some instances to express a need for improved institutional care for the dying. Palliative Care for oncology patients in many urban centres of South Africa can be accessed by most of the population as the local Hospice movement, with its focus on PC, is a non-profit organisation servicing the entire population, regardless of income (Clark et al 2007).

In rural areas of South Africa however, Hospice care is thinly stretched where it is available, and tends to focus efforts on people with AIDS and their dependents (Clark et al, 2007). Urban areas in South Africa have easier access to a wider range of Hospice services, including some limited in-patient facilities such as those offered by the St Luke's Hospice for the greater Cape Town area. Towns and cities in South Africa are also better equipped with diagnostic and treatment resources, including acute care hospitals that may be State-run or privately run, and accessible only to people who are able to pay for services received.

2.2.2.5 Acute Care Hospitals and Palliative Care

The provision of PC in acute care hospitals, or oncology clinics where treatment is generally of curative intent is a challenge (Ewing, Farquhar and Booth, 2009). In certain instances, patients may receive anti-cancer treatment such as radiation therapy or chemotherapy, but with a palliative rather than curative intent – this difference is not always well understood by patients, or by PC professionals who are unfamiliar with the potential symptom relief certain treatments may provide (Davis, 2005). The complex role of anti-cancer treatments in PC is outlined by Davis (2005), who concludes that comprehensive cancer care should include aspects of both curative and Palliative Care, preferably via a process of discussion, negotiation and cooperation between practitioners.

The need for specialised education and training of all levels of staff in PC has been highlighted in an attempt to improve the quality of care available to patients (Dowell, 2002; Clemens, Kumar, Bruera, Klaschik, Jaspers and De Lima, 2007; Gwyther and Rawlinson, 2007; Stjernswärd and Gómez-Batiste, 2008). Some of the problems encountered in acute care hospitals include the fast-turnover of patients in wards and using staff members who are frequently unaccustomed to the complexities of caring for people who will die soon (Dowell, 2002; Lagman, Rivera, Walsh, Le Grand and Davis, 2007). In addition, the problem of frequent staff rotations in acute care wards is mentioned by Stark (2011) as this may interrupt relationships with patients and family, and disrupt the continuity of care for the dying person.

Costello (2006) highlights the roles and perceptions of nursing staff in caring for the dying in an acute care hospital, and emphasises the vulnerability of nurses to personal distress and their

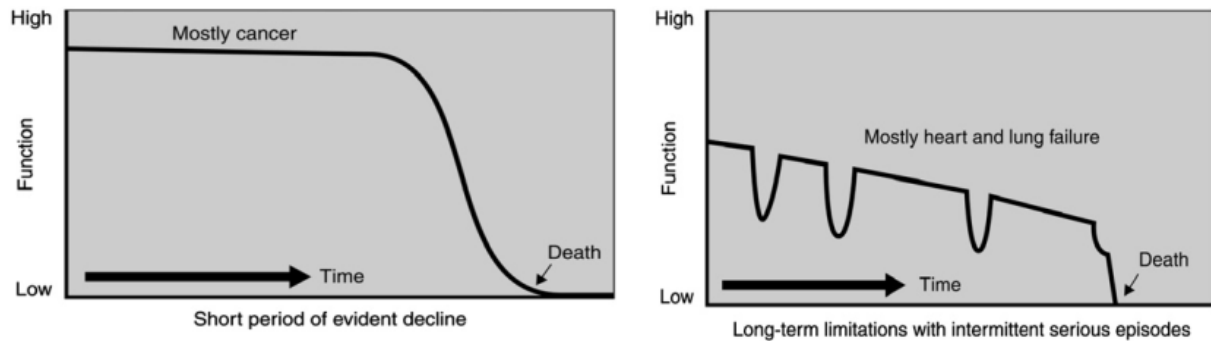
anxiety about coping with other patients who may be aware of the death in the ward, as well as practical management of the dead body. The recommendations from this article include the importance of improving communications with patient and family about the expected course of the illness (the imminence of death), and the suggestion that patients become more involved where possible in expressing their wishes about their care whilst in the ward (Costello, 2006). Patients and family members may find approaching death an unfamiliar prospect, and are uncertain how to cope with the deteriorating condition of the patient. From clinical experience, it is apparent that family members especially appreciate sensitively-shared guidance about what to expect or anticipate during the dying process, and may even welcome the opportunity to discuss this phase of illness as part of their preparation for the death of the patient.

2.2.2.6 The dying process

Preparing for death from cancer is a process that involves all aspects of a person and family's beings – there are multiple physical, emotional, social, cultural, spiritual and economic factors to be considered. Most people with advanced cancer and their family have not encountered these challenges before and are uncertain how to prepare, desiring certainty and guidance about how to manage situations that may arise.

One way of helping people cope with the lack of certainty, whilst remaining realistic about approaching death, is the concept of a Dying Trajectory which graphically depicts the average expected course of certain illnesses prior to death (Teno, Weitzen, Fennell and Mor, 2001; Lynn and Adamson, 2003), indicating the downward trend in condition as opposed to a specific time frame or precise course of the illness. The use of illness trajectories can also assist health care professionals to plan patient care more realistically (Murray et al, 2005) as well as provide a discussion tool for patients and their family. The graphical representation below of the declining condition for people with advanced cancer or other chronic conditions indicates how swiftly and continuously a condition can change. This type of illustration, when used in conversation with the patient or with family members, may assist people to prepare for death as they are able to review the change in condition using a visual tool.

Figure Two: Hypothesised trajectories of the physical decline in patients with advanced cancer, compared with those with other chronic conditions



(From Higginson and Constantini, 2008, based on Lynn and Adamson, 2003)

Dying of cancer may be an extremely sudden (and therefore difficult to predict) event such as a fatal bleed, but is generally preceded by a period of deterioration in the physical or functional status of the patient (Teno et al, 2001; Constantini et al, 2008). This is clearly indicated in the trajectory illustration above, where patients may experience a rapid decline in overall condition in the weeks before death. The rate of physical decline along with the increase in the number of symptoms may assist with prognostication, with a recent study suggesting that on average the functional decline in adult cancer patients begins about twelve weeks prior to death, regardless of the age of that patient (Constantini, Beccaro and Higginson, 2008).

The issue of providing a time frame remains an uncomfortable topic for medical professionals who are known to frequently make inaccurate estimates of life expectancy (Stone and Lund, 2007). In terms of patient care, it is often helpful to the patient and family to have an indication of what the prognosis may be in order to assist with decision-making, and preparations for the patient's demise (Stone and Lund, 2007).

Much as the work of Palliative Care is to prepare the patient, carers and family for declining health as death approaches, the physical dying process may remain a mystery to many, especially in a social context where people are unfamiliar with illness and may not have witnessed a death before. Woof, Carter, Harrison, Faull and Nyatanga (1998) advise that conversations with patients and carers around this topic take place honestly and with caution, addressing three goals:

to discuss fears or concerns realistically; to help the carer feel better able to cope with the dying itself by planning appropriately; and to assist the carer to identify appropriate and accessible professional support should this be necessary, as in the case of a home death.

The last week of life is usually characterised by the patient becoming bedridden, often being semi-conscious and difficult to rouse, able to only manage limited liquid intake (literally sips or mouthfuls), and the patient generally not being able to swallow oral medications (Ellershaw and Ward, 2003). Provided there is no aggressive medical intervention during this time, and the patient is kept comfortable, the overall decline in physical condition will continue and life is not sustainable for many days.

Wood and Fox (2005) discuss care needs of patients as well as physical signs that will indicate to carers that death is approaching within a few days or hours. In lay terms some of the observable changes that provide clues that death may be imminent include metabolic changes (for example disturbed sleep patterns, restlessness), a decrease in muscle tone especially in the limbs, altered sensory functioning including impaired vision, possible changes in breathing patterns, a difference in bowel and bladder elimination and in the amount of respiratory secretions, and diminished or slowed circulation (Wood and Fox, 2005). Not all of these signs are present prior to death, but frequently when several of the signs are observed, it is fair to predict that death is days or hours away. If this information can be conveyed to family members or carers, they are afforded the opportunity to prepare for the death in terms of ritual or presence at the time of death. The importance of calmness and reassurance for the family members or carers present is emphasized by Wood and Fox (2005), with support from members of the extended medical or Hospice team being particularly helpful where possible and appropriate.

The chapter by Woof et al (1998) gives more medical and technical information, as does the article by Kehl (2008) which highlights aspects of care and how both the patient and family can be supported during the final hours prior to death. The role of medication to relieve symptoms can be helpful, whilst the administration of un-necessary medications during the dying phase should be halted (Woof et al, 1998). Basic physical care can be planned and organised to minimize patient distress, while optimising comfort and symptom relief, with family members

being encouraged to participate in this care where desired (Kehl, 2008). Reassurance of the dying patient may require physical contact or the creation of a peaceful environment, whilst reassurance for the family and friends may include supportive updates, emotional containment and the provision of information about the process being witnessed (Woof et al, 1998).

Of importance to relative and friends of the dying person may be the probable changed extent and quality of communication with the dying person. This may feature a social withdrawal or lack of interaction even if the patient is conscious, which may be distressing for witnesses who are not prepared (Kehl, 2008). The style of communication or conversation from the patient may alter, and be reduced to short phrases or sentences rather than lengthy interactions, which may be hampered further by generalised weakness or confusion, making understanding by carers difficult. Additionally, it has been observed that patients may use symbolic references or language in their communications, which are open to interpretation by their family members (Kehl, 2008).

In preparation for dying, it is understandable that many patients will experience a range of emotions, amongst which may be a sense of multiple losses as life draws to a close, possibly accompanied by various fears (Parkes, 1998). The losses may include a loss of personal safety, physical condition and independence, self image and self esteem, a loss of physical strength and energy, the potential loss of respect from other people or a sense of being undignified, and the loss of a personal future (Parkes, 1998). In terms of individual fears faced by the dying patient, there is a combination of practical and relationship fears listed: separation fears (from people, roles, employment); not being able to complete tasks, dreams or goals in life; a fear of being a burden and of losing control of self and of independence; a fear for the continued well-being and care of dependents; fear of pain and physical symptoms; fear of dying itself and of being dead; and the fear of witnessing the distress and fear in others (also described as reflected fear) (Parkes, 1998).

2.2.2.7 Planning ahead for death

As the study explored how family members experienced the death of a person dying of cancer, it is helpful to consider how planning may be possible in order to have care plans or financial and business arrangements in place before the death itself. The word “planning” is used broadly here to explore discussions and communications between various parties and to discuss some of the difficulties with decision-making. Finally, there will be mention made of the role of Integrated Care Pathways in the caring for the imminently dying.

2.2.2.7.1 Communications

Aside from the obvious imperative that the terminally ill cancer patient be kept as comfortable as possible (Byock, 2000), the importance of honest and clear communications between medical staff, the patient and the patient’s carers has been emphasised repeatedly and links to the right of the patient for information about their condition and prognosis (Edmonds and Rogers, 2003; Friedrichsen, 2003). Several valuable roles of clear communications between role players in PC are listed by Jeffrey (1998a): maintenance of trust between people, the minimization of uncertainty, allowing expectations to be reality-based, promoting emotional adjustment for the patient and family members, and to limit possibilities for silence, suspicion or secrecy (Jeffrey, 1998a). Rainer and McMurray (2002) explore several practical and important aspects of supporting people facing death, and present a helpful guide to communicating as a professional with patients and families. Included in this list is the reminder that clear and honest communications help to promote emotional containment and allows conveys a message of acceptance and support to the patient or carer (Rainer and McMurray, 2002).

Hebert, Copeland, Schulz, Amato and Arnold (2008) focus on the potential for social workers to assist family members with preparation for death by being a conduit of communication whilst providing psycho-social support and helping connect caregivers with resources. The need of caregivers for various types of information during the patient’s terminal illness can be met by social workers who are well placed to communicate, educate and support patients and families throughout this process (Hebert et al, 2008). The social worker’s role in PC includes providing or accessing information, and assisting with communications and acting as an advocate when required, promoting or supporting patient decisions, and attending to practical needs of the

patient and family (Monroe, 2004). It follows that clear communications between medical professionals and the patient-system will enhance the ability to make decisions about care needs and preferences.

2.2.2.7.2 Decision making

Planning ahead when facing a terminal illness, should include the possibility of providing clear instructions or information about the wishes of the patient and family that are understood by all involved in the patient's care (Lang and Quill, 2006). In situations where communications have been open and constructive, there may be the opportunity for the patient to discuss preferences with family members or carers about minor, as well as major concerns – these could range from conversations about decision making, to place of care and place of death, and may extend to more specific details about the extent of medical interventions preferred (Bakitas, Ahles, Skalla, Brokaw, Byock, Hanscom, Lyons and Hegel, 2008).

A Medical Power of Attorney, Durable Power of Attorney for Health Care or Health Care Proxy can be established by the patient, empowering a trusted person to make medical and care decisions on their behalf at such time that the patient is unable to do so, although this does not necessarily include end-of life decisions (Duba and Magenta, 2008; Kirsch, 2009). This provision may provide the PC team with a clear indication of what the patient wished should there be decisions to be made regarding their care (Kirsch, 2009).

An indication of Advanced Care Planning, where clear decisions have been made about future care is the completion of an Advanced Directive, or Living Will (Lang and Quill, 2006; Duba and Magenta, 2008). An advantage to having a Living Will in place is that the signatory will have discussed its contents, or at least made the presence of the Living Will known to family members, carers and ideally to members of the medical team including the patient's general practitioner who may have known the patient over an extended period of time (Lang and Quill, 2006). A study conducted retrospectively in the 1990's suggested that people who had a Living Will were more likely to die outside of hospital than those without Living Wills who were found to die more commonly in hospital (Degenholtz, Rhee and Arnold, 2004). The implication is that the act of expressing preferences about end of life care may assist family and medical staff with

honouring the patient's expressed wishes although the Living Will does not specifically state preferred place of death (Degenholtz et al, 2004). South African law does not recognise a Living Will or Advance Directive (Norval and Gwyther, 2003) although people do have access to such forms and may lodge them or discuss them with health practitioners.

A combination of excellent communications and provision for decision making when the patient is unable to do so for themselves should contribute towards improved end-of-life care. Integrated Care Pathways have been developed to provide clear care directives.

2.2.2.7.3 Integrated Care Pathways

Patients who die in hospital and their family members have special needs that are sometimes not met by the medical teams working with those patients, resulting in the impression that care is sub-optimal (Edmonds and Rogers, 2003; Ellershaw and Ward, 2003; Sorenson and Iedema, 2011). Extending from the Hospice model of care, a sequence of decision making and actions by the medical team, known initially as the Liverpool Care Pathway, was developed to assist dying cancer patients in the last two days of life (Luhrs and Penrod, 2007). This concept has since been developed further and has been instituted in nursing homes as well as hospices and acute care hospitals in the United Kingdom, the United States and in parts of Europe (Luhrs and Penrod, 2007).

Essentially, Integrated Care Pathways require a multi-disciplinary approach to the end-of-life care, with consensus required at the outset that the patient is in fact imminently dying (Ellershaw and Ward, 2003). From this point, a clinical care plan is put in place, incorporating good communications with the patient's family, a review of medications and medical interventions, and ongoing emotional and physical support for both patient and family (Ellershaw and Ward, 2003). The patient's condition is regularly observed and monitored for symptoms which should be alleviated by nursing interventions and/or medication as required (Edmonds and Rogers, 2003), with careful documentation and reviewing of the care process ensuring adequate and appropriate support (Luhrs and Penrod, 2007).

The care of people with advanced cancer does not fall only to medical professionals in a hospital setting. The patient who has progressive disease may require an increasing amount of assistance, and may become fully dependent on others for all aspects of care. Such support and care can be provided within the home environment, and family members or close friends are frequently required to become carers. In contrast to trained nurses and professionals, this group of people is referred to as “Informal Carers” or “Informal Caregivers”, and face their own challenges with specific needs, as will be outlined in the following section.

2.3 Family members as Informal Carers

This study relies on responses from family members, or significant others identified as Next of Kin. When working with dying patients, members of the patient’s family can be identified by the social worker, together with that patient, allowing for social or cultural ties and not purely biological connections to determine the status of a family member (Glajchen, 2011). As the focus of the study was on the dying process of the patient, and the circumstances surrounding that dying, it was important to understand the role of family and friends as carers during the patient’s terminal illness which may have changed and developed in complexity during the illness process (Given, Given and Kozachik, 2001; Glajchen, 2011). A useful definition of an Informal or Family Caregiver (or Carer) is provided by Harding and Higginson (2003) who explain that such carers are not paid, and are required to provide practical, physical and emotional care and support to the terminally ill cancer patient. These tasks may be supported by local community resources, or may be carried out away from resources and professional guidance (Cain, Maclean and Sellick, 2004; Aoun et al, 2005; Hebert and Schulz, 2006). In more developed areas such as the United States and Australia, caregiving is becoming increasingly recognised as an important role in society, with the majority of Informal Carers being women (Mackinnon, 2009; Wilkinson, 2010, Glajchen, 2011).

In resource-poor areas, support from health care professionals may be scanty leaving Informal Carers to manage the dying patient with whatever familial or social assistance is available (Gysels et al, 2011). The same authors focus on care in sub-Saharan Africa, and conclude that ongoing care for the dying by immediate and extended family is no longer the automatic preference in communities, with a criticism that home-based care can easily deteriorate to

become “home-based neglect” (Gysels et al, 2011; 7), particularly in areas where health care systems are poorly established.

There are four main areas where caregivers are required to function, namely direct care for the patient, business or administrative tasks, organisational requirements and needs related to the caregiver’s personal functioning (Eatmon, 2002). Towards the end of the patient’s life, it may become increasingly difficult to find a balance between these tasks, especially if patient care is round the clock and demanding (Andersson, Ekwall, Hallberg and Edberg, 2010). What may follow is stress symptoms, potential carer burn-out and depression (Eatmon, 2002; Tilden, Tolle, Drach and Perrin, 2004). These symptoms, together with sleep disturbances, the effect of witnessing what they perceive to be suffering and a sense of feeling emotionally and physically confined by their caring responsibilities is described as being “Caregiver Strain” (Tilden et al, 2004).

2.3.1 The needs of Informal Carers

The needs and concerns of Informal Carers have been addressed in literature since the mid- to late 1990’s, with some specific needs being unique to the caring situation and some being personal needs which are often unmet (Given et al, 2003; Soothill et al, 2003). Needs of the Informal Carers may have been overlooked by health care professionals in the past, and are only recently being assessed as patient’s family is considered to be an extension of the patient in terms of care and support needs (Cain et al, 2004; Glajchen, 2011). In situations where there are several unmet needs or where needs are not being met over a period of time, the carer’s ability and capacity to care for the patient may be diminished unless the professional health care team members attend to these needs (Soothill et al, 2003). This finding is repeated in the works of other authors who have explored needs of the Informal Caregivers (Glajchen, 2004; Cain et al, 2004). In the recently published Oxford Textbook of Palliative Social Work, a chapter is dedicated to helping the social worker understand the complexity of the role of Informal Caregiving, which includes sections on understanding the socio-cultural environment, and assessing the individual motivations, needs and challenges of an Informal Caregiver (Glajchen, 2011).

The need for information and practical advice regarding caring and what to expect in the dying process has been identified by several authors, with suggestions for addressing these needs varying from teaching and training sessions (Glajchen, 2004), to support groups for carers (Glajchen, 2004), to information sheets for family members (Cain et al, 2004; Glajchen, 2011), to practical help and advice from both the broader community and the medical team (Mangan, Taylor, Yabroff, Fleming and Ingham, 2003).

Alongside informational and supportive needs, there are practical and personal needs of Informal Caregivers that are frequently neglected as the focus remains on the patient and their wellbeing. Specific personal needs of the Informal Carer include medical attention for existing or new complaints (Grunfeld, Coyle, Whelan, Clinch, Reyno, Earle, Willan, Viola, Coristine, Janz and Glossop, 2004; Sjövall, Attner, Lithman, Noreen, Gunnars, Thomé and Olsson, 2009), relief from extreme fatigue and disturbed sleep patterns (Tilden et al, 2004), and restoration of disrupted social and civic lives (Girgis, Johnson, Aoun and Currow, 2006). It has been found that particularly the lack of private time and self-care can lead to loneliness, social isolation and altered relationships, and the sense of loss and grief for the changes already encountered as being separate from the imminent death of the patient (Girgis et al, 2006).

The religious and spiritual needs of Informal Carers has been documented, and form an integral part of assessing the overall coping and resources of those caring for the terminally ill (Woof et al, 1998; Tanchel, 2003). At a time when mortality is being faced by the patient, family and friends may have their own belief systems tested. Pearce, Singer and Prigerson (2007) refer to religion as being a belief system that is used especially at times of personal anxiety and uncertainty, often using religious practices such as prayer or associated rituals to help them cope with challenges. It has been suggested that caregivers may see their role of caring as being a means of religious service, which can improve their personal coping and sense of satisfaction, although these carers may also take on additional responsibilities and feel burdened in their attempt to fulfil religious duties (Pearce et al, 2007). In contrast, the same authors found that People who believed themselves to be abandoned by God, or a Higher Power, or believed their situation to be a punishment, usually experienced a poorer quality of life, found the caring more burdensome and reported a lower level of satisfaction in their caregiving role than those who had

more positive religious coping styles (Pearce et al,2007). Regardless of the presence or absence of religious practices, the availability of religious and/or spiritual support for Informal Carers remains an important component in their overall coping and is in turn essential to the Palliative Care provided to the patient and family system (Tanchel, 2003; Callaway and Ferris, 2007).

2.3.2 Spouses as Informal Carers

Spouses (or life partners) of the dying cancer patient may carry multiple responsibilities as the Informal Carer, the person managing the couple's domestic life and personal affairs, and often the person in charge of communicating with friends and family about the patient's condition. It is estimated that spouses who are caregivers provide four times as much care as do other family members who provide care, thereby reducing the spouses' time and energy resources to pursue activities away from the patient (Glajchen, 2011).

In addition to the physical and social burden of being an Informal Caregiver, the spouse caregiver has the challenge of emotionally processing and preparing for the end of a significant relationship in their life (McLean and Jones, 2007). The relationship bonds and attachment systems within the marriage or partnership become more intensely activated by the presence of advanced, life-threatening cancer, and this may trigger anxieties about separation, or insecurities and distress, depending on the nature of the relationship prior to the illness (McLean and Jones, 2007; Braun, Mikulincer, Rydall, Walsh and Rodin, 2010). The extent of and style of attachment within the spousal relationship can be a predictor of difficulty in spouse care giving, and authors Kim and Carver (2007) recommend that additional education and information may assist spouse caregivers to improve their skills. Secure attachment within the marital relationship should enable the spousal carer to provide responsive care, as opposed to insecure attachments that tend to lead to low level responsiveness in caring for the terminally ill partner (Kim and Carver, 2007; McLean and Jones, 2007).

Individual responses to the task of informal caregiving as a spouse vary. Risk factors for higher levels of caregiver stress include the direct tasks of caring, as well as poor caregiver health, and poor quality or reduced social contacts (Haley, LaMonde, Han, Burton and Schonwetter, 2003). Factors regarded as protective against excessive caregiver stress include more a flexible approach

to the caregiving responsibility, overall personality style of the spouse and their coping style, and the presence of supportive social networks or supports (Haley et al, 2003). The complexity of the spousal-carer and patient relationship may feature negative and positive interactions which may alternate between partners but often include a concern for the other person above concern for self (Mackinnon, 2009).

It may be ill-advised to attempt generalisations at comparing how men or women cope as spousal-carers of terminally ill life partners. However, some studies on this topic have been undertaken and have found that gender and established roles in the relationship may influence the couple's coping with the cancer illness itself (McLean and Jones, 2007). Female partners are noted as being at higher risk than male partners for psychological distress (Sutherland, 2009; Glajchen, 2011). In contrast, male caregivers are less likely to accurately represent their own caregiver strain to others, and may under-report the symptom severity of the patient (Fromme, Drach, Tolle, Ebert, Miller, Perrin and Tilden, 2005).

Whatever the nature of the relationship, Glajchen (2011) stresses the importance of not making assumptions when working with spouses or family members as carers – a thorough assessment of the relationship's strengths and weaknesses will assist with identifying and providing appropriate support. It is known that the experiences, challenges and conflicts that people encounter during caring for a terminally ill person, will impact on that individual's bereavement process, making professional support and access to services through the illness process of significant value (Grande and Ewing, 2009; Holtslander and Duggleby, 2010).

2.3.3 Support for Informal Carers after death of the patient

Informal Caregivers require not only information and support during their time of caring for the dying patient, but also require professional support after the death and during bereavement (Grbich, Parker and Maddocks, 2001; Grande and Ewing, 2009). The lack or absence of information and support for Informal Carers during the patient's illness has been found to impact negatively on the grieving process of the Informal Carer (Grande and Ewing, 2009).

When Informal Carers have experienced a death at home they may feel exhausted in a physical and emotional sense, and may express a lack of purpose and a lack of focus since their caring role ended (Grbich et al, 2001). These feelings can be normalised and supported by professionals in order to facilitate the grieving process which Informal Carers may not understand in terms of its duration and complexity (Grbich et al, 2001; Grassi, 2007). It is suggested that professional interventions to assist the bereaved and prevent the development of additional psychological problems may include: listening actively to the bereaved person's narratives, providing information and responding to questions from the bereaved, and providing practical guidance or direction where necessary (Grassi, 2007).

2.3.4 Psychiatric risks faced by Informal Carers

As discussed above, the Informal Caregiver to a terminally ill patient has managed several additional responsibilities and tasks over a period of time, depending on the patient's condition. This sometimes-lengthy period of involvement and caring will require changing roles, many personal sacrifices and a measure of uncertainty about the duration of the illness process ahead (Glajchen, 2011). The caregiver may find that the burden of care becomes increasingly onerous as the patient's physical condition declines (Grunfeld et al, 2004), at times leading to a near-exhaustion on the part of the caregiver, who may then seek in-patient care for the patient, partially as a means to obtaining some respite for themselves (Wheatley and Baker, 2007). At times of such depletion, the caregiver may manifest symptoms of distress, with the additional risk of developing depressive symptoms (Braun et al, 2007) that may be further debilitating.

Anxiety is commonly encountered in Informal Caregivers who may have concerns about symptom management, feeling the burden of trying to keep the patient comfortable while mastering new skills in terms of practical care or medication administration (Glajchen, 2011). Time pressures to carry out caring duties while trying to run a home and possibly manage a job or parental roles will also add to the sense of anxiety and panic that caregivers report (Glajchen, 2011). Uncontained anxiety, coupled with physical fatigue and possible fear or helplessness may add to caregiver distress and the sense of being over-burdened (Grbich et al, 2001), again contributing to psychological distress.

It follows then that the Informal Caregiver may have become socially isolated and lonely due to their protracted caring responsibilities (Cain et al, 2004; Rokach, Matalon, Safarov and Bercovitch; 2007). Their regular coping skills and support systems may be depleted so that there is vulnerability in Informal Caregivers during bereavement in terms of potentially developing psychiatric and/or physical illness (Vanderwerker, Laff, Kadan-Lottick, McColl & Prigerson, 2005; Grassi, 2007; Dumont, Dumont and Mongeau, 2008). Several authors have focussed on the risk of depression for caregivers of patients with cancer, citing the potential impact of depression on physical health and quality of life if it is not diagnosed and managed (Rivera, 2009). Spouse caregivers are especially identified as being at risk of developing depression, or other psychiatric morbidities post-bereavement (Braun et al 2007; Sjövall et al, 2009).

2.3.5 The cost of being an Informal Carer

Whilst common-sense logic would suggest that caring for an ill person in a home environment, with Informal Carers in place should be the most cost-effective way of providing end of life care, researchers have reviewed this and have concluded that there is additional financial strain placed on households providing home-based care (Hayman, Langa, Kabeto, Katz, DeMonner, Chernew, Slavin and Fendrick, 2001; Aoun et al, 2005; Hanratty, Holland, Jacoby and Whitehead, 2007). The financial challenge faced by Informal Carers is encapsulated in the need by many carers to maintain their own paid employment, whilst managing the increasing care-needs of the dying person at home (Cain et al, 2004; Hanratty et al, 2007; Glajchen, 2011). Additional to this is the cost families may have to meet for additional medication, rental of equipment and medical supplies (Aoun et al, 2005), with some families reporting that a large amount of family savings were required as additional income during the illness process (Phipps, Braitman, True, Harris and Tester, 2003). The financial strain experienced while providing care for a terminally ill person contributes to sense of caregiver burden (Tilden et al, 2004).

There are several contributors to the financial burden that patients and families face when providing care at home including the extensive use of personal savings with resultant financial pressure on the patient and or family, reduced income due to working shorter hours or stopping work to provide care, and conversely, taking on additional paid work to help meet expenses (Tilden et al, 2004). Additional to these pressures are out-of-pocket expenses that are necessary

to provide care at home: medications, unscheduled transport costs, equipment hire and the expense of additional help at home (Tilden et al, 2004).

In the South African context, there are additional costs to be borne if the family of the patient chooses to employ additional help with caring for the patient. Such costs will vary according to the type of help sought, and the extent of assistance available from funders such as medical aid schemes (Wood and Fox, 2005; Manicom, 2011). Although home nursing care for a person with end-stage cancer does not require the services of a registered nursing sister, the employment of a person with nursing skills can become costly, and the possibility of recovering costs from the patient's medical aid may be dependent on several qualifying factors. Government-funded Home Based Carers are only permitted to work in homes which fall within a certain income bracket, and Hospice services are available to all for nominal or no charge, but cannot provide daily nursing care at home. The extra financial burdens carried by families of dying patients in this country therefore are very similar to the lists above (Wood and Fox, 2005).

2.3.6 Some of the benefits of being an Informal Carer

Despite the challenges of caring for a terminally ill person in a home environment, many Informal Carers are able to identify benefits, or advantages to managing end stage care without requiring hospital or institutional admissions (Milberg and Strang, 2003; Sinding, 2003; Morasso, Costantini, Di Leo, Roma, Miccinesi, Franco Merlo and Beccaro, 2008). There are several positive aspects to Informal Caregiving which are identified by Morasso et al (2008) including improvements in family dynamics such as better relationships between those involved in the caring process. The development of a more satisfactory relationship between the Informal Carer and the dying person can be viewed as a mutual benefit (Morasso et al, 2008; Phillips and Reed, 2009). The following benefits of providing Informal Caregiving at home were identified by Glajchen (2011): the opportunity for personal growth, possible enhancement of the carer's sense of self worth, and the satisfaction of undertaking and completing the task as carer. Together with the potential sense of satisfaction, may be the obligation or duty to provide care, in accordance with cultural or religious requirements (Hosking et al, 2000; Morasso et al, 2008). It has been suggested that some Informal Carers are able to derive comfort and will attempt to minimise future regrets, by undertaking the caring role, thereby honouring familial and social

roles, and demonstrating to themselves and others that they were dutiful and loyal in their role as Informal Caregiver (Sinding, 2003).

In considering the advantages of being an Informal Caregiver to a person dying of cancer at home, Sutherland's article (2009) identified three concepts that could be extended to any person preparing for the death of someone close to them: making meaning from the caring process; initiating and following the process of anticipatory grief; and carrying, finding and living with hope.

With preparation, support and education, it is possible to assist and enable Informal Carers to carry out their commitment to home care (Stajduhar and Davies, 2005). From the review of literature above it is clear that the Informal Caregiver has a key role to play not only in providing physical and nurturing for the dying person, but also in enabling that person to remain in their home environment until death, if that is the preferred Place of Death.

2.4 Place of Death

Some research articles into Place of Death (POD) may concentrate on governmental mortality figures and data (Davies et al, 2006; Hanratty, Burstrom, Wallander and Whitehead, 2007) while others rely on information gathered specifically related to limited geographically, demographically or otherwise-defined areas (Bruera, Russell, Sweeney, Fisch and Palmer, 2002; Davies et al, 2006). As a result of these differing data sources, study sizes have ranged from less than 100 subjects (Thomas, Morris and Clark, 2004), to whole populations with thousands of cancer deaths (Burge, Lawson and Johnston, 2003; Grundy, Mayer, Young and Sloggett, 2004; Davies et al, 2006).

There have been works that analyse trends in POD, particularly as a reflection on government policy or funding of community or palliative care services (Decker and Higginson, 2006; Constantini, 2008). Certain articles also use POD as a vehicle for commentary on the social support system in existence within geographical regions (Bruera et al, 2002; Burge et al, 2003; Davies et al, 2006; Gomes and Higginson, 2008). Several authors from Europe and North

America have concluded that home death is more likely if there is better access to material and medical resources and social support, with the implication that lower socio-economic status will contribute to a higher number of “away from home” deaths (Brazil, Bedard and Willison, 2002; Grunier, Mor, Weitzen, Truchin, Teno and Roy, 2007).

In order to respect the individual patient’s right to determine where they will be cared for during the terminal phase of their cancer, it is essential for the health care professional to discuss this in advance with patient and loved ones, and for this preference to be recorded in the patient’s medical notes, with reviews and discussions about this preference from time to time (Brazil, Howell, Bédard, Krueger and Heidebrecht, 2005; Constantini, 2008; Duba and Magenta, 2008). The field of Palliative Care seeks to provide patients with dignified, respectful terminal care as far as possible in accordance with the patient’s wishes, as discussed ahead of the terminal events themselves (Schachter and Coyle, 1999; Thomas, 2005; Nieu Meyer and Hosking, 2006).

Many families may attempt to honour the patient’s wishes as far as possible, and will go to great lengths and personal sacrifices to ensure death at home (Brazil et al, 2002). People who have Living Wills or Advance Directives in place are also more likely to die in their own homes than those who do not (Abernethy, 2008; Bell, Somogyi-Zalud and Masaki, 2010).

Where access to medium- to long-term care is limited, or in short supply, there may be high incidence of end-stage admissions to acute care hospitals of patients cared for, until then, at home (Yun, Lim, Choi and Rhee, 2006; Hallenbeck, 2008). In certain circumstances, poverty, overcrowding and sanitation issues make home deaths difficult to envisage and support (Hebert and Schulz, 2006). By contrast, information about death in Kampala, Uganda, suggests that government hospital facilities at the time of the study were so poor in the early 2000’s that death at home was preferable to death in a State owned facility (Kikule, 2003). There may be cultural preferences for, and societal expectations of death amongst one’s own kin rather than in the relatively impersonal space of a hospital or nursing home (Seale, 2000; Phipps et al, 2003; Cohen, Bilsen, Addington-Hall, Löfmark, Miccinesi, Kaasa, Onwuteaka-Philipsen and Deliens, 2008).

In urban settings within developed countries, studies on the POD of people with cancer indicate a strong tendency towards death away from home, in a hospital setting (Bruera, Sweeney, Russell, Willey and Palmer, 2003; Decker and Higginson, 2006). By reflecting on factors that contribute towards hospital deaths, authors have highlighted the need for improved social and policy structures to encourage and promote home care of the dying cancer patient (Gallo, Baker and Bradley, 2001; Bruera et al, 2003). The exception to this observation appears to be certain Scandinavian countries where community support and domiciliary Hospice care is well established (Aabom, Kragstrup, Vondeling, Bakketeig and Støvring, 2005; Hanratty et al, 2007).

Across the world there are variances in place of death, with changes in trends and influential factors being noted from a sociological perspective (Seale, 2000). Amongst the many reasons why people may not be cared for until death in their own homes are: limited assistance at home, a lack of knowledge and/or skills on the parts of informal carers in a home environment (Fukui, Fukui and Kawagoe, 2004; Stajduhar and Davies, 2005; Gomes and Higginson, 2006; Agar et al, 2008). Factors directly related to symptom management have been found to influence Place of Death (Bell et al, 2010) with pain control being a particular concern for the Informal Carers (Given et al, 2001). A sudden change in the patient's condition may also precipitate and unscheduled hospital admission (Wheatley and Baker, 2007). Some of the ethical problems posed by trying to uphold patient autonomy while considering the difficulties inherent in providing home care in some instances are presented by Wheatley and Baker (2007). These authors discuss potential risks to the patient, the carers or the medical staff in certain situations where it may be necessary to limit the options for place of care, and ultimately place of death.

Gender differences in place of death have been reported on briefly in some articles (Carlsson and Rollison, 2003; Gatrell, Harman, Francis, Thomas, Morris and McIlmurray, 2003; Gagnon, Mayo, Hanley and MacDonald, 2004; Howat, Veitch and Cairns, 2007) with the importance of social support being noted as a factor predicting home deaths for women (Izquierdo-Porrera, Trelis-Navarro and Gomez-Batiste, 2001). The age, fitness and availability of carers in the form of life partners, or family members also become factors in terms of home care (Grundy et al,

2004). Willingness and ability of family members to become Informal Carers of a dying loved one has also been studied, along with information needs of the carers (Cain et al, 2004) and have been found to be enablers of home death where this is the patient's preference (Karlsen and Addington-Hall, 1998). The commitment of family members and carers to assisting the patient towards a death at home also requires community support (Karlsen and Addington-Hall, 1998) and good palliative home care which would include support from medical resources such as health visitors, and the family physician (Brazil et al, 2002).

It is also argued that in more sophisticated societies, the dying process itself has become more "sanitised" and so that nursing a dying person at home is an uncomfortable consideration and families prefer death to take place within the confines of a hospital setting (Bowling, 1983; Hallenbeck, 2008). Certain authors have gone further and suggest that dying as a process is virtually denied by medical professionals, who may continue to view death as a failure (Clark, 2007).

Wherever a person dies, and there has been any element of choice in determining the POD, the over-riding hope for patient, family and professional team (where present) is that the death will be good, in terms best understood by that person's community and culture. Studying and defining a Good Death has become an additional area of interest and study among sociologists, psychologists and palliative care practitioners.

2.5 Good Death

The term "Good Death" may appear to be an oxymoron, and is variously described by patients, their families and by professional medical teams working with the terminally ill (Henwood, 1999; Smith, 2000; Kehl, 2006; Miyashita, Morita and Hirai, 2008; Leung, Liu, Cheng, Chiu and Chen, 2009). Terminologies describing the process of death may allude to a Good Death, but may be framed in differing words by the author in question. For example, Poss (1981) refers to dignity in death and outlines six tasks or conditions to be accomplished by the dying person in

order to die with dignity. These tasks are considered to be inter-related, but can be listed individually:

- 1) Develop an awareness of approaching death
- 2) Establish a balance between a sense of hope and of fear
- 3) Through awareness and reflection, make the decision that physical survival is no longer possible and death is therefore inevitable
- 4) Surrender of responsibilities and the giving over of independence
- 5) Embark on a separation of the self from previous and past experiences, moving into a here and now reality
- 6) Prepare spiritually for death.

(Poss, 1981)

2.5.1 The historical development of concept of Good Death

The Institute of Medicine in the United States published a document in 1997 that provided a definition of Good Death and suggested standards for care of the dying (Institute Of Medicine, 1997). The definition set by the Institute of Medicine includes avoidance of distress and suffering as far as possible for all involved, requires that the patient's and families' expressed preferences be observed, and that the death itself is in line with existing standards of clinical care, cultural norms and ethical requirements (Institute Of Medicine, 1997).

Emanuel and Emanuel (1998) used this document as a departure point to provide a framework of structures and processes in the patient's care system that should be in place to ensure a good death. This framework uses as a baseline the basic characteristics of the patient, then adds aspects of that person's experience and reviews the care and support systems in place. This combination then forms the composite experience of the individual's dying process. In addition, the same authors provide some practical guidelines for those working with the dying, which should facilitate a Good Death (Emanuel and Emanuel, 1998). This article concludes with four items of advice for clinicians involved in care of the dying: a thorough assessment of the dying person and their whole situation is essential; excellent knowledge and skills in palliative care is a basic requirement; care of the dying is not the preserve of doctors alone and a team-approach

including professionals and the patient's social support network is ideal and the practitioner should be mindful of the impact of death on the broader community (Emanuel and Emanuel, 1998).

A study in the United Kingdom in the late 1990's led to the compilation of a document specifically describing care for older people, but setting out twelve principles considered essential to a Good Death (Henwood, 1999). This document, together with the Emanuel and Emanuel article, have been quoted in subsequent studies on Good Death, in different countries and cultures (Steinhauser, Christakis, Clipp, McNeilly, McIntyre and Tulsky, 2000; Edmonds and Rogers, 2003; Costello, 2006; Kehl, 2006; Miyashita et al, 2008; Leung et al, 2009; Tayeb, Al-Zamel, Fareed and Abouellail, 2010).

The principles outlined by Henwood can be listed (1999) as follows:

A Good Death is one where the dying person

- 1) Knows that death is approaching, and understands what to expect from the process
 - 2) Is able to have some control over the dying process
 - 3) Has dignity and privacy in death
 - 4) There is control of physical symptoms including pain
 - 5) Has choice about place of death
 - 6) Has sufficient expertise and information available during the dying process
 - 7) Has spiritual and emotional support available as required
 - 8) Has access to the services of Hospice in their place of care
 - 9) Has choice and control about who is present at time of death, and for the hours preceding this
 - 10) Is able to discuss and compile advance directives regarding their end-of-life care, and to have these preferences upheld
 - 11) Has sufficient time to say goodbye and to have a sense of control over timing of leave-taking
 - 12) Not to have life prolonged unnecessarily, so that death occurs as naturally as possible.
- (Henwood, 1999)

These principles have been used as the basis for the formulation of the questionnaire to be used in this research, and are referred to in Chapter Three.

There is also literature that reviews the needs of palliative care and medical professionals to contribute towards a Good Death, especially as medical interventions become more technical and awareness of patients' and family rights has increased (Clark, 2002). For the purposes of this research, publications reviewing Good Death in Intensive Care or similar situations have been avoided, with the researcher focussing on Good Death for patients with cancer who are cared for in the community or in conventional medical wards as these conditions most closely match those of the respondents in the sample surveyed. Deaths in highly technical, mechanised and electronic environments, such as Intensive Care units, have different components, as well as aspects to care and ethical decisions to be considered in terms of potentially prolonging life or not. The deaths in this study were typically "low-tech" in terms of not including life support mechanisms.

Much has been written in general about what constitutes quality end-of-life care, and what factors may be necessary to facilitate a Good Death (Emanuel and Emanuel, 1998; Steinhauer, et al, 2000; Jack, Jones, Jack, Gambles, Murphy and Ellershaw, 2004; Kehl, 2006; Miyashita et al, 2007). A comprehensive list of factors considered important by the disciplines of Sociology, Theology, Medicine and Nursing is outlined in Kring's article (2006) and emphasises the overlapping of factors and determinants of a Good Death from an academic point of view. Excluded from this work are the disciplines of Social Work, Psychology and Psychiatry, which all encounter challenges in understanding and assisting to achieve Good Death (Kring, 2006).

Walter's (2003) brief article on historical and cultural contexts and their impact on the individual perception of a Good Death provided a Sociological overview that highlights the fact that such perceptions may change with time. Bradbury's (2000) work suggested that Good Death in a modern Western culture could be regarded in one of three categories, dependent on the perspective of the observer. Bradbury (2000) further describes a good Sacred Death in which the dying person is emotionally and spiritually conscious and is prepared for death, a good Medical Death which requires comfort for the unconscious patient who has relinquished control of care to

the medical team, and a good Natural Death which would feature either an unexpected painless death, or a situation where the dying person has some control and active participation in the dying process, such as decision making or specification of wishes prior to dying.

In order to understand what a Good Death means or comprises to individuals or groups, it is helpful to have an indication of what is important or meaningful to those people. This understanding is best gained through frank enquiry and open communications.

2.5.2 Communications as part of preparation for a Good Death

Patient autonomy, independence, a sense of control over events and decision making, together with open communications form the ethical and moral central focus for Good Death principles that are recognised in a predominantly Western culture (Henwood, 1999; Clark, 2002; McNamara, 2004; Costello, 2006). Linked to these ideals is the presumption that the patient, family members and health care team recognise and understand that death is imminent so that conversations about choices and preferences can take place. Literature describes this prognosis of imminent death as “Diagnosing Dying” (Ellershaw and Ward, 2003), which skill is associated with doctors and nursing staff. These authors specify that for competent care of the patient and family, the multi-disciplinary medical team needs to be in agreement that the patient is in fact dying, which enables the style of medical of care to alter and requires honest discussion with the family members and loved ones (Ellershaw and Ward, 2003).

There are some publications and guidelines for the public available which help to describe the physical dying process (Wood and Fox, 2005), and the Kehl (2008) article gives specific, clear and clinical descriptions of bodily indications that a patient has few hours left to live.

Communication with the patient (if they are conscious and responsive) and with family or loved ones should be conducted honestly, with the practitioner being mindful of cultural and religious sensitivities (Tanchel, 2003; Costello, 2006).

Some of the care challenges occur when there is a discrepancy between the medical team’s palliative care approach and the patient and/or family’s individual need for choice or independence in decision-making (McNamara, 2004). The work outlines the potential conflict

between medical advice and patient autonomy, which may reduce the opportunity for a Good Death, to have it replaced by what McNamara calls a “good enough death” that is acceptable to family and patient, above the preferences of the medical team.

Work done by researchers in different countries has found that dying people and their families hope for similar attributes to be present to enable a Good Death, and that dying at home is only one of several factors (Steinhauser et al, 2000; McNamara, 2004; Kehl, 2006; Kring, 2006; Miyashita et al, 2007, Tayeb et al, 2010). While it is evident that there are common themes in the concept of a Good Death, this concept remains a subjective one and one that is perhaps elusive in societies where death is seldom discussed or is avoided as a reality, making its presence unfamiliar, unwelcome and often overwhelming (Holland, 2011).

The circumstances surrounding the death of a loved one may be carried into the grieving process by those who remain and can influence their period of bereavement and adjustment following their loss (Chochinov, Holland and Katz, 1998; Dumont et al, 2008).

2.6 Grief and Bereavement

To help understand some of the psychological dynamics inherent in this study, the researcher believes that it is helpful to have a general insight into the complexity of grief, and an appreciation of the fact that emotional processing of loss may begin before the loss occurs and may continue for many months after the loss has taken place.

The human experience of loss varies and may therefore be expressed differently according to the type of loss being faced and the individual’s life stage, cultural and social circumstances (Parkes, 1988; Worden, 2002; Holland, 2011). The three terms found in Western literature related to commentary on responses to loss are described by Walter (1999) as being bereavement, grief and mourning. Bereavement is the experience of having lost a person to death (Holland, 2011). The second term is grief which describes the emotional response to, or experience of loss which could include material, role, status, and relationship loss (Holland, 2011). The third term is mourning which refers to the social behaviour encountered after bereavement (Walter, 1999) and is usually

perceived as being a process through which the bereaved pass in adjusting to their loss (Worden, 2002; Holland, 2011).

In Western medical settings, human responses to the death of a person have been subject to specific observation since the late twentieth century when care of the dying became a focus of attention (Kübler-Ross, 1969; Illich, 1976; Seale and Cartwright, 1994; Kellehear, 2007).

Bereavement theories may outline stages in the grief process, or tasks associated with it (Kübler-Ross, 1969; Parkes, 1988 and Worden, 2002). Rothaupt and Becker's article (2007) provides a historical overview of bereavement theories, including contemporary theorists and drawing attention to gender and cultural differences in bereavement. In the South African context, an understanding of some of the cultural responses to grief and bereavement is helpful for the professional involved in Palliative Care (Hosking et al 2000; Drenth, Herbst and Strydom, 2010).

2.6.1 Anticipatory Grief

When death is attributable to cancer, there may be a period of preparation for that death when the patient becomes increasingly frail making both patient and family are aware of the imminence of death (Parkes, 1988). This may be referred to as the terminal phase of the cancer illness, and can vary in duration from weeks to days or hours. During such an apparent decline in the patient's condition, family members and significant others often begin their grieving process and emotionally ready themselves for their loss and this is known as Anticipatory Grief (Chochinov, Holland and Katz, 1998; Grassi, 2007). However, not all cancer deaths follow a gradual or predictable path, and sudden death due to cancer can also occur. In the instance of a sudden cancer death, it is possible that the bereaved may experience significant psychological disturbance (Chochinov et al, 1998; Hedlund and Clark, 2001).

2.6.2 Pathologising of Grief

There is a difference between reactive sadness to the death of a loved one and depression. This statement may appear obvious, but there is concern in current literature that sadness or low mood following a death may be misinterpreted and incorrectly managed as depression (Gerbino and Raymer, 2011).

As mentioned in the section on Informal Carers, this group of people are at risk for depression during and after their period of caring. Those who have undertaken care giving of a family member with advanced cancer may experience extreme fatigue and exhaustion in their grief, partially attributable to the period of protracted caring (Schachter and Coyle, 1999; Stajduhar, Martin and Cairns, 2010). It follows then that during bereavement, family caregivers of the deceased may experience a decline in their physical health status with factors such as older age increasing the likelihood of poorer health (Brazil et al, 2002). Physical symptoms and ailments can be seen as a reflection of the psychological stress and distress the bereaved person faces (Worden, 2002) and the development of illness is not unexpected in situations where the family members have been caregivers for a protracted period of time, often neglecting their own well-being (Glajchen, 2004).

It is beyond the scope of this review to provide an outline for assessing for depression in the grieving adult, but it remains important for professionals working with the bereaved to thoroughly understand the complexity of the individual's loss before diagnosing depression (Holland, 2011).

2.7 Conclusion

This literature review has outlined some of the key concepts and constructs that will be encountered in the course of this research document. The review began with a broad overview of the field of Psycho-Oncology, and narrowed that down to an exploration of some of the work done in the specific arena of Palliative Care. From there the researcher included work done on the role and challenges facing Informal Carers who were targeted as potential respondents in the postal questionnaire used to gather data for the research. Thereafter an examination of aspects influencing Place of Death was presented, followed by discussion about the concept of Good Death. Finally, there was a brief exploration of some of the background and current concerns around Grief and Bereavement.

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CHAPTER THREE

Methodology

3.1 Introduction

Chapter Three outlines the Methodology employed to conduct this study, beginning with an overview of the Research Design selected. The Sampling technique is discussed followed by an explanation of the Data Collection method used in the questionnaire. The Structure of the Questionnaire is outlined and the administration of the Pilot Study is discussed. There is information on techniques used in the Data Analysis for the study, and an exploration of the Limitations of the Study precedes the Conclusion.

3.2 Research design

Formal research requires structure and objectivity to formulate a conclusion, following a scientific process and adhering to ethical and academic standards (Brink, 2009). Research designs are categorised into Qualitative and Quantitative approaches, dependent on the style and format of the overall design, the role of the researcher, the data collection tools employed, the measurement and interpretation of the results. Both approaches have advantages and can be used in the Social Sciences to reliably gather information that will contribute to the body of knowledge about the chosen topic (Brink, 2009; Fouché and Delpont in de Vos et al, 2010). Having considered both research approaches, the researcher elected to use a Quantitative Research approach.

Quantitative Research has several characteristics that can be listed:

- Concepts to be focussed on are tightly defined and are kept few in number
- The starting point for the research is a suggestion or notion about how the concepts to be studied are related, or may impact one another
- Formal data collection instruments are used following a clear research structure and research procedures
- Information for the study is gathered in controlled manner under specified conditions
- Data collection and analysis is objectively undertaken
- Analysis of information is numeric using statistics

- The researcher is non-participant in the research process, so is present to gather data but not to interact with or intervene with the participants
 - Logical and deductive reasoning are used to draw conclusions from the results.
- (Brink, 2009)

From the above list, it is evident that Quantitative Research has as its focus the measurement of behaviours and utilises statistical analysis of information which has been gathered in a structured, controlled manner (Brink, 2009). This study used the Quantitative Research approach to objectively and confidentially collect information from the family members of deceased patients, relying on a postal questionnaire to gather information and analysing this information using descriptive statistics. Due to the emotionally sensitive nature of the subject matter, it was decided to use the questionnaire to collect data as this allowed respondents privacy as they considered their responses in their own homes, without any investigator present. Additionally, the fact that questionnaires remained anonymous enabled people to express themselves without restriction or fear of judgement. Blank questionnaires were returned and were counted as refusals to participate. Several respondents added their own comments or opinions, suggesting that they felt comfortable sharing information with the researcher. By using the Quantitative Research approach, the researcher was able to extract information directly from as many respondents as chose to participate, whereas the sample size would have been smaller had a Qualitative Research approach been employed.

Brink (2009) explains that a Non-Experimental research design may be utilised to record occurrences in the setting in which they occur naturally, without controlling the research environment. The setting in which this study was undertaken required observations from respondents regarding the death of a person either at home or in an acute-care hospital setting. There was therefore no manipulation of variables by the researcher who retrospectively requested subjects to respond to written enquiries about their recollections about the events and circumstances surrounding the death of the patient. This approach is therefore compatible with a Non-Experimental research design and can further be classified as descriptive research, meaning that the focus of the study is on a naturally occurring phenomenon (Brink, 2009), namely the death of someone due to cancer. Descriptive research can assume a variety of designs, using

different data collection techniques including observation, questionnaires, interviews and survey studies without relying on an intervention from the researcher (Brink, 2009). In terms of Brink's (2009) review of descriptive research designs, this study can be categorised as a Comparative Descriptive Study as data from two groups of respondents will be compared to answer the Research Questions.

3.3 Sampling

In a research context, the concept of sampling refers to the extraction of a group of participants or subjects who are considered representative of a larger population (Strydom in de Vos et al, 2010).

3.3.1 Research population defined

According to Brink (2009) and Strydom (in de Vos et al, 2010), the term population refers to the entire group of people who share characteristics that the researcher plans to study. It was necessary to obtain permission from GVI Oncology to use patient records to source potential participants to form the research population. The letter of permission is attached as Appendix A. In this study, the research population comprised people who fitted five essential criteria for inclusion:

- a) The person noted in the deceased patient's original registration form as a GVI Oncology patient, under the category of "Next of Kin" was deemed to be a possible participant in the study.
- b) Only Next of Kin of patients known to have died either at home, or under the oncologist's care at Constantiaberg Mediclinic were included in the study.
- c) The potential respondent required a traceable address in order to be mailed a questionnaire.
- d) The research population was limited in size as it was additionally restricted to a specific time-frame, namely death of the patient between 01 January 2008 and 31 October 2010.
- e) The deceased patients had to be over the age of 20 and have died of cancer or direct complications – other causes of death not attributable to cancer (for example: heart attack, suicide or motor vehicle accident) were not included.

Quantitative Research requires an accurate measurement of responses and a rational approach to gathering information, so requires the researcher to clearly explain who will be involved in a study and how the subjects will be selected. As most researchers are practically not able to scrutinise every person in their research population, the concept of sampling has been developed to scientifically select a subset or smaller number of people from within the population, who are then used as the pool from which the research data is drawn – this pool of people is referred to as the sample (Strydom in de Vos et al, 2010). This will now be discussed.

3.3.2 Sample population

By requiring participants in the study to complete a questionnaire, quantitative methods were used to objectively obtain responses from the sample population. Probability sampling was utilised to ensure that every person in the research population had an identical probability of being selected for the study (Strydom in de Vos et al, 2010). One of the benefits of probability sampling as defined by Brink (2009) is that the sample derived from the research population will closely represent the original research population.

The technique used to obtain the sample for this study is known as simple random sampling which has three criteria: there is a single stage selection process for the sample; every subject has the same chance of being included; and the research population is clearly defined (Brink, 2009).

Each of the above three criteria is described in the context of the study. The first step in the selection process occurred in a single stage when the list of potential respondents was compiled, according to the criteria already provided. Details of deceased patients, their next of kin and their postal addresses were obtained from medical records by the researcher as part of the preparation for the study. The second criteria for simple random sampling was met as every person approached to participate in the study had an equal chance of being included in the sample. Finally, the research population was defined as being the group of people whose cancer-related loss occurred during the calendar years of January 2008 – October 2010, with the death of the patient occurring either at home, or in the Constantiaberg Mediclinic whilst under the care of the Oncology practice.

The research population itself was homogeneous in terms of being English speaking, being generally middle-class to wealthy, and living in established and older suburbs of the Southern Suburbs in Cape Town. Nardi (2006) suggests that in more homogeneous samples there is a greater chance of establishing a representative sample from a smaller group of people.

As the population of the study was narrowly defined, the entire research population was approached to participate in the questionnaire, with those successfully completing and returning the questionnaire constituting the sample.

A total of 204 questionnaires were sent to next-of-kin requesting participation in the study. With 15 returned as address unknown, there were 189 potential respondents in the sample population. The total number of returned questionnaires was 64, with five refusals to participate and one that did not fit the place of death criteria, giving a sample size of 58.

3.4 Data collection

Data was gathered from the responses received by the researcher. Respondents were provided with stamped, address envelopes together with the questionnaire, enabling them to send the completed pages directly to the researcher at a post office box. This reduced cost and effort for respondents, with the aim of improving the overall response rate.

Additional strategies to improve the response rate to postal questionnaires in a health care context have been examined by previous researchers, yielding some commonly practiced strategies:

- 1) Questionnaire length, with improved response rates with shorter questionnaires
- 2) Reminder strategies to encourage participation, which could include telephonic or postal follow-ups
- 3) Incentives to complete and return the questionnaire, including monetary incentives.

(Edwards, Roberts, Clarke, DiGuseppi, Pratap, Wentz and Kwan, 2002; Nakash, Hutton, Jørstad-Stein, Gates and Lamb, 2006).

In the current study, attention was focused on making the questionnaire as succinct as possible, and as easy to interpret and respond to as possible with the intention of encouraging a good response rate.

As the questionnaire in this study presented emotionally provocative questions, the researcher did not use a follow-up letter or use a repeat mailing to respondents, although this strategy has been used to good effect elsewhere (Jacoby, Lecouturier, Bradshaw, Lovel and Eccles, 1999). The anonymous nature of the questionnaire meant that responses could not be directly traced unless people provided identifying details. More importantly, the researcher believed that it would be potentially distressing to send reminders given the content and the fact that recipients may have simply chosen not to respond in any way.

Finally, the researcher considered it unethical to offer any type of incentive or motivator to people completing the questionnaire, relying rather on their own desire to express themselves, or to share information that may be helpful and improve future care of other terminally ill patients and their family members.

3.4.1 Postal questionnaire

In order to collect information researchers may use techniques such as experiments or content analysis, or may use tools such as surveys and questionnaires (Fouché and de Vos in de Vos et al, 2010). This Quantitative study posed questions and gathered information by means of a postal questionnaire, analysing the findings to form a conclusion.

The use of questionnaires to gather facts and opinions from respondents is a valid and commonly employed method of data collection in quantitative research (Brink, 2009; Hofstee, 2009; Delpont in de Vos et al, 2010). This approach has been used by other researchers to investigate opinions of family members about the dying process (Addington-Hall, Walker, Jones, Karlsen and McCarthy, 1998; Jacoby et al, 1999; Miyashita, Morita and Hirai, 2008) so is an established technique in the Palliative Care field. By selecting a self-completed postal questionnaire as the tool for gathering data, the researcher demonstrated respect for the participant's right to privacy, with respondents being able to provide clear written responses to questions posed. These responses were measurable and quantifiable when being analysed, according to a pre-determined

Data Analysis Plan which Kruger, de Vos, Fouché and Venter in de Vos et al (2010) recommend is formulated before the Data Collection stage begins.

Despite a traditionally low rate of return, postal questionnaires have been shown to be a useful means of collecting information from family members about palliative care received by a dying patient (Addington-Hall et al, 1998; Jacoby et al, 1999), so this was considered to be a satisfactory vehicle of enquiry for the current study.

The final sample size represented 33.9% of questionnaires dispatched. This was an adequate percentage given that postal questionnaires are known to have poor response rates with figures as low as 5% to 20%, with returns of less than 30% being considered normal by some writers (Fowler, 1993; Delpont in de Vos et al, 2010). It has been suggested that 20 to 30% people will respond quickly to mailed questionnaires (Nardi, 2006) and that this figure could be increased by the use of reminders (Delpont in de Vos et al, 2010) although this strategy was not employed, for reasons previously discussed. The response rate for this study is discussed in more detail in Chapter Four.

3.4.2 Design of the questionnaire

The use of a written questionnaire allowed the researcher to capture opinions and experiences from a group of people who had similar shared experiences. This form of data collection is described as being a self-report instrument (Brink, 2009). In addition to questions being posed, statements may be included in a questionnaire (Delpont in de Vos et al, 2010). In designing this questionnaire, the researcher had purposefully kept the format of questions and statements as brief as possible, and was able to limit the entire document, including the introductory message to four A4 pages. The questionnaire can be found in Appendix B.

The questionnaire was carefully constructed, following research principles in order to extract workable data (Delpont in de Vos et al, 2010). A correctly designed questionnaire will clearly fit the objectives of the research topic, will align the contents of the questionnaire with the research objectives and the research problem, and will seek to obtain the most appropriate and correct information possible whilst being mindful of the limitations of time and resources (Brink, 2009).

One of the benefits of using a questionnaire to collect data is the standardised format for questions and responses, which eliminate interviewer bias (Brink, 2009). The structure of a research questionnaire should receive careful attention to ensure good compliance, prevent ambiguity in responding to questions, and to encourage participation by keeping the appearance of the questionnaire simple and easy to complete (Brink, 2009). The use of individually mailed questionnaires provided the respondents with a sense of anonymity which enabled them to be more frank in their responses (Brink, 2009; Clark-Carter, 2010) and the researcher anticipated this would encourage a good return rate of completed questionnaires. Each questionnaire had brief introductory and explanatory paragraphs, followed by the body of the document which comprised a total of four pages. Stamped addressed envelopes were included without any identifying marks or details on them to ensure confidence of the respondent in the anonymity of their response.

When collecting data, the researcher should have a clear idea of how responses will be gathered and measured in order to obtain the desired information (Delpont in de Vos et al, 2010). Closed questions provide a limited range of choices for response, and allow for easier comparison of responses during data analysis. They are quicker to code than free-text or open questions but by their nature restrict possibly more complex or in-depth responses (Delpont in de Vos et al, 2010). By contrast, open questions encourage the respondents to use their own words, and can provide a wider range of information than a simple one word answer provided to a closed question (Delpont in de Vos et al, 2010). In order to prevent there from being an overwhelming array of lengthy responses, the researcher used a combination of closed and open questions in this study, restricting the number of open questions to two only at the end of the questionnaire. Likert-type scales are an example of intensity measures, giving a choice of degree of agreement with a statement or question (Nardi, 2006). The researcher used a five-point Likert-type scale to assess agreement to the statements in the questionnaire, thereby allowing respondents the opportunity to rank their responses.

Clark-Carter (2010) advises that structured questionnaires, with formally constructed questions are of particular use when approaching a subject that has previously been well studied. The researcher established that several questionnaires have been compiled and analysed for use in

studying the quality of end-of-life care, as well as recording the perceptions of observers of the quality of the dying process itself (Albers, Echteld, de Vet, Onwuteaka-Philipsen, van der Linden and Deliens, 2010; Hales, Zimmerman and Rodin 2010). There have also been studies into what factors groups of people such as Palliative Care teams, and family members consider to contribute towards a Good Death (Henwood, 1999; Kehl, 2006; Miyashita et al, 2007; Leung et al, 2009).

The report entitled “The Future of Health and Care of Older People: The Best is Yet to Come” (Henwood, 1999) contains a chapter on considerations around the End Of Life, which includes a list of twelve Principles ideally present in a Good Death. Kehl’s (2006) article reviews 42 published works on the concept of Good Death and identifies a list of twelve factors most commonly regarded as being contributors towards a Good Death. A combination of these Henwood’s (1999) principles and Kehl’s (2006) factors formed the basis for the questionnaire that was used to collect data from people who experienced either death at home or in the Constantiaberg Mediclinic under the care of the oncologist.

The second section of the questionnaire consists of Question 11 to Question 18 and required respondents to reflect specifically on the last week of the dying person’s life. The questions took the form of a five-point Likert scale, indicating the degree of agreement with the statement posed. The intention of this section was to consider practical preparation and support in the final week of life, together with the sense of personal support the respondent experienced. The statements in this section referred to how the respondent experienced the final week of the dying person’s life, so included general care and perceptions of support received, irrespective of where the physical caring took place.

The format of the statements was designed to narrow down the respondent’s thinking and recollection around the death itself, using statements extracted from existing literature on contributors to a Good Death. Several sources were consulted to compile the list of questions with the sources being selected that would reflect what the researcher anticipated the respondent’s world view to be. To expand on this comment, there have been articles published on perceptions of a Good Death in parts of China (Leung et al; 2009) and in Japan (Miyashita et

al; 2008), and although interesting, the researcher elected not to use these materials as cultural variances with the current group of respondents would be high.

In order to substantiate the theoretical base from which the statements in Questions 11 to 26 were extracted, the table below summarises the two references specifically consulted and links them with the statements in the questionnaire. In terms of cultural appropriateness, the previously mentioned report from Henwood (1999) reflected on end of life care in England while the article quoted by Karen Kehl (2006) originated in the United States and represents a review of forty-two articles focussing on the concept of Good Death, should represent similar opinions on Good Death to those of the respondents to this questionnaire.

Table One – Sources for statements included in postal questionnaire

	Henwood 1999	Kehl 2006	Question number in current study
Sense of control regarding health care decisions, including advance directives	✓	✓	Questions 12; 21
Patient choice respected regarding place of care/death, people who may be present	✓	✓	Questions 17, 18, 24, 25
Access to expertise, information	✓	✓	Question 13
Comfort including physical and emotional care	✓	✓	Questions 22, 23
Opportunity for closure and preparedness for death	✓	✓	Questions 11, 19, 20
Acknowledgement of the patient as a whole person with value, including dignity	✓	✓	Question 26
Relationships with carers, including medical team		✓	Questions 12, 13
Access to Hospice care at home or as in-patient	✓	x	Question 16
Readiness and acceptance of imminent death	✓	✓	Questions 11, 19, 20
Upholding of personal spiritual, moral, cultural beliefs	✓	✓	Question 14
Presence and availability of emotional support	✓	✓	Question 15
Ensuring lowest physical and financial burden on others	x	✓	Question 13
Possibility to allow for relationship completion	x	✓	Questions 19, 20
Death itself being as natural as possible	✓	✓	Question 21
Sense of patient being remembered, being honoured for contributions	x	✓	x
Care for the family before, during and after death	x	✓	x

3.5 Structure of the questionnaire

The essence of this study is to retrospectively gather information about the next-of-kin's perceptions of the dying process and death of a patient with cancer. As it was not possible to collect the deceased's observations or experiences, the researcher's use of people close to the deceased constituted the use of proxy respondents. This means of data collection has been utilised by other researchers (Addington-Hall and McPherson, 2001; Kutner, Bryant, Beaty and Fairclough, 2006) and has found to be a satisfactory investigative technique in the absence of the patient themselves.

Questions and statements were worded and framed to encourage responses, and to be easily understood by respondents of different backgrounds. All instructions were in English and required a literacy level of approximately early secondary school. The questions were phrased to elicit the opinion of the respondent as person most likely to have been closest to the dying person (identified as Next of Kin on patient's registration form). The responses indicated the opinion and perceptions of lay people who have lost someone close to them to cancer.

The questionnaire was designed in four parts: basic demographic particulars and information around place of death; responses to statements about the last week of the decedent's life; and responses to statements about the final 24 hours of the decedent's life followed by a statement and a question about the respondent's perception of Good Death.

Questions 1 – 10: These closed questions established the basic demographic information and details of the patient's death. No opinions were sought and factual responses were required. A combination of dichotomous and multiple choice questions was used, with two questions requiring specific answers if known to the respondent. Tick boxes were provided for the dichotomous and multiple choice questions.

Questions 11 – 18: These statements called for reflection on the last week of the patient's life, with a five-point Likert Scale provided for ranking the level of agreement or disagreement with the statement offered.

- Questions 19 – 26: The statements in this section focussed on final 24 hours of the patient's life, with a five-point Likert Scale provided for ranking the level of agreement or disagreement with the statement offered.
- Questions 27 – 28: The questions contained two open ended questions about the respondent's perception of death allowing for free text responses.
- Question 29: The final closed question requiring Yes, No or Not Sure response to whether respondent believed this have been a Good Death or not.

There was space provided at the end of the questionnaire and on the backs of pages for additional comments or remarks.

In terms of addressing the Research Objectives, as set down in the Research Questions, the questionnaire was constructed to specifically address the four questions posed in Chapter One:

- 1) Where did the patients from a private oncology unit die during the period 01 June 2008 – 31 October 2010? This was answered by Question 5 in a tick box response – choice of Home, the Constantiaberg Mediclinic or Other.
- 2) How did the family members experience their loved one's death? This was answered by Question 27, and allows for free text response.
- 3) How would family members define a Good Death? This was answered by Question 28, and allows for free text response.
- 4) Do the family members consider this death to be a Good Death? This was answered by Question 29, with a tick box response – Yes, No, or Not Sure.

The statements and responses were selected for Questions 11 onwards to establish whether, with supportive process a Good Death is attainable. The supposition here is that Good Death is not entirely reliant on place alone but has other contributory factors.

3.6 Pilot study

In preparation for a research project, it is necessary to conduct a Pilot Study which serves as a test run for the data collection tool, using a smaller sample than that used for the full research (van Teijlingen and Hundley, 2001; Brink, 2009; Clark-Carter, 2010; Strydom in de Vos et al,

2010). The term “feasibility study” may also be applied to a Pilot Study, particularly where the research or findings require funding and the results of the Pilot Study may be presented as a motivation to funders for support (van Teijlingen and Hundley, 2001).

The pilot study enables the researcher to detect possible errors and shortcomings in the design of the study, ambiguities in the wording of questions and to identify potential procedural problems in the data collection process (Brink, 2009). There are additional uses and benefits of undertaking a comprehensive and well-planned Pilot Study, as listed by Strydom in de Vos et al (2010) and by van Teijlingen and Hundley (2001). These potential benefits include an assessment of the suitability of the data collection tool, the opportunity to establish what the response rate may be to the questionnaire, the possibility of collecting preliminary data and the potential to review planned data analysis techniques (Teijlingen and Hundley, 2001; Strydom in de Vos et al, 2010).

Participants in the Pilot Study should match the sample population as closely as possible, and may not be approached with the final questionnaire (Strydom in de Vos et al, 2010). Responses to the Pilot Study are used to review the survey or questionnaire itself, and may form the basis for modifications to the final questionnaire, but are excluded from the final Data Analysis. If there are several modifications or changes to be made to the questionnaire, it is possible to conduct a second or third Pilot Study until there is satisfaction on the part of the researcher that the final questionnaire and allowing the data collection process to proceed as smoothly and accurately as possible (Strydom in de Vos et al, 2010).

In this study, the researcher mailed 15 questionnaires to people listed as “Next of Kin” for patients known to have died at the St Luke’s Hospice in Kenilworth. By making this selection, the sample population was not diminished, but identifying particulars such as time frame for the death and death with advanced cancer remained constant. The questionnaire that was used for the Pilot Study is attached in Appendix C. Responses were reviewed with attention to items that were incorrectly answered or were difficult for people to understand. The questionnaire was modified before being sent out in its final form, which was shorter than the Pilot questionnaire

with clearer numbering of questions. Statements were phrased more directly and with less ambivalence to encourage simpler responses.

3.7 Data analysis

Brink (2009) and Kruger, de Vos, Fouché and Venter (in de Vos et al, 2010) explain that data analysis is the process of taking the raw data that has been collected, organising it and working with the data to present a summary that will enable the researcher to interpret the results. Data analysis on its own is not the end result of any study, but is a step towards achieving a conclusion (Kruger et al in de Vos et al, 2010).

In quantitative research where data is presented in numerical form, statistical analysis may be used to process the data (Brink, 2009). Descriptive statistics are used to not only describe data that has been collected, but are able to provide additional detail based on additional calculations (Brink, 2009). The researcher used descriptive statistics to present an overview of findings such as averages and percentages, medians and ranges of data, as well as the distribution within the results. Statistics were calculated by the researcher using the Microsoft Excel computer programme.

Without a clear summary of the data collected, this study will have no basis for further commentary or future action. Data collected for a quantitative study remains a "... chaotic mass of numbers" until it is statistically processed and presented (Brink, 2009; 171). The use of descriptive statistics therefore will enable the researcher to numerically and visually present the findings and to then discuss the findings in greater depth. Use is made of pie charts, bar graphs, histograms and frequency tables to illustrate findings. In order to be academically and scientifically acceptable, it is necessary to follow established conventions in terms of calculating and presenting the statistics (Kruger, de Vos, Fouché and Venter in de Vos et al, 2010), with raw data being stored separately and included as Appendix D.

Recognising that no piece of academic work is without its challenges and shortcomings, the limitations of the study will now be discussed.

3.8 Limitations of the study

Hofstee (2009) explains that all academic works have limitations which affect the extent to which conclusions can be extrapolated, or not. By setting out the limitations of this study, the researcher will outline the boundaries within which the work has been carried out. The limitations of this study can be listed as follows:

3.8.1 Research design

Proponents of Qualitative Research may argue that the use of Quantitative techniques to gather opinion and record observations can be limiting in terms of the richness and depth of detail in responses gathered (Hofstee, 2009). It is true that a questionnaire cannot elicit and record detailed responses, but the use of a questionnaire allowed the researcher to reach a larger number of respondents than would have been possible with personal interviews or focus groups (Nardi, 2006). The anonymity of a written questionnaire also encouraged honest responses, and provided objective information for analysis (Nardi, 2006).

3.8.2 Sampling

Fouché in de Vos et al (2010) lists among possible limitations for a research study the access to data. In this study, the researcher experienced some lack of access by virtue of incorrect contact details for next of kin of deceased patients. This resulted in the non-delivery of questionnaires, with the consequence that a smaller number of people were approached to participate in the study. This limitation was unavoidable as it is not uncommon for people to move home following a death, particularly if there are security or financial concerns for the survivor. The researcher made use of available resources like telephone directories or patient case notes to try to trace family members, but this was not always successful.

As the decedents in this study were all patients of a private health care oncology unit, there is a presumption of some financial means and a middle- to upper-class socio-economic status of respondents. This fact, together with the sample size limits the potential for generalising the findings to the broader South African community, however, the information gathered has direct application for similar privately run oncology units in other urban areas of South Africa, such as the seven other units managed nationwide by the GVI Oncology group. Whilst not being

necessarily representative of the South African population, it can be argued that this study has obtained reasonable representation of the study population which Fouché in de Vos et al (2010) states as being desirable when undertaking research.

An additional consideration with this study is the time frame used for inclusion. The researcher elected to approach people whose bereavement was at least twelve months prior to the survey. There was the possibility of difficulty of recollection for those with longer-standing losses, and there was the probability of painful recollections for those with recent losses who may still be grieving acutely. Work by other authors indicates that recollections can still be accurate and valid years after bereavement, making survivors a reliable source of information (Krajnik, Szymanowska, Adamczyk, Kozaka, Skrzypski, Szostakiewicz and Jassem, 2008). The opportunity for debriefing was offered to all respondents, and the introductory paragraphs to the questionnaire stated clearly that participation in the survey was voluntary.

3.8.3 Data collection

Basic information containing names and addresses of deceased patients was gathered from medical records and was incomplete in places. The researcher sought to obtain missing information where possible, but there were some details that could not be established thereby limiting the research population size. After sending out the postal questionnaires, several were returned by the Post Office with incorrect addressee details, and this further reduced the eventual sample size for this study. Such logistical challenges are inevitable when working retrospectively over a period of several years and again will limit the potential to generalise the findings to other populations.

An additional benefit of using a questionnaire that can be completed in the respondent's private space and time is the opportunity it provides for reflection, in a population that may be emotionally vulnerable. The anonymity of the questionnaire may have allowed for more honest reflections and for the expression of concerns or the provision of feedback for improvement, which respondents may have felt less comfortable voicing in a face-to-face interview situation.

The self-limiting aspect of this study that cannot be avoided is the reliance on others to assess or interpret the dying process of a third party. It would be interesting and helpful to know how dying people themselves experienced their care but this information is understandably difficult to access. Respondents were required to act as representatives for the deceased, noting their own observations and perceptions, which is an established technique for assessing end of life experiences and has been utilised by other authors (Addington-Hall and McPherson, 2001; Bakitas et al, 2008).

3.8.4 Data analysis

Data was analysed in terms of background information about the respondent and the deceased, and in terms of that person's experience of being involved in the dying process. The background information collected and presented in this study does not include specific socio-economic data, which limits the possibilities of comparing findings to other studies where factors such as race, income or education level may have been included. Basic demographic information about the respondent and their relationship to the deceased was requested in the questionnaire and was gathered to establish averages and ranges for respondents' characteristics. As the study focused on observations about the dying process and death itself, the researcher focused on individual responses rather than demographic tendencies, working from the basis that death is a universal phenomenon and people from various backgrounds may experience it in different ways, possibly dependent on circumstances. It can also be argued that very few quantitative studies can be replicated in terms of data gathered and how it was analysed. This study is not attempting to mirror findings or compare results directly with other works, and retains its focus on the process of dying rather than demographic details of the deceased or the next-of-kin.

Linkages between frequencies of responses and possible relationships between variables were not sought in this exploratory study which set out to gather information and opinion about factors that may contribute towards the perception of a Good Death. Therefore, more complex statistical reviews such as correlations have not been undertaken. Future research could explore potential relationships between variables.

3.8.5 The researcher

The researcher has inherent limitations of time and resources, being a fully employed person and essentially undertaking this study as a solo researcher. Many of the studies referred to in this proposal have been undertaken by large academic teams in settings where the focus is research and not clinical work. However, this study was purposefully kept small to keep the information relevant to one particular setting where findings could be directly conveyed to professional teams involved in the care of the dying cancer patient.

3.9 Conclusion

This chapter has provided an outline of the methodology employed in this study, including an explanation of the research design with its use of quantitative research techniques. The sampling process was discussed followed by a detailed description of the data collection process. The structure of the questionnaire is explained. Following this explanation, the use of the pilot study is presented. The methods used in data analysis are outlined and a description of the limitations of the study concludes this chapter.

This study presents an enquiry into perceptions of the Next of Kin had about the dying process of a person with cancer, set in the context of a private health care facility in the Southern Suburbs of Cape Town. There has not been any similar work done in this country, as far as the researcher can establish, and this does not pretend to be an exhaustive or definitive piece of work. However, with a clear research methodology, using quantitative research techniques and a simple questionnaire design, the researcher believes that the findings presented in the following chapter will have relevance to other health care teams and will provide indications for possible future improvements in service, and potential for future research which will be discussed in the final chapter.

CHAPTER FOUR

Findings and Discussion of Findings

4.1 Introduction

This chapter will present the findings from data gathered in the postal questionnaires returned to the researcher. The findings will be presented sequentially, following the format of the questionnaire and discussion on findings will follow. Descriptive statistics have been used to analyse data, with attention to percentage representations where totals are not equal, thereby allowing for a more accessible comparison between figures. Where calculations have been made, use has been made of one decimal place after the point, necessitating the established practice of standardising figures by using the practice of rounding off. The total number of respondents per question or category is denoted by the letter N , with n_1 being used to indicate the number of respondents from the Home Death (HD) category and n_2 indicating the number of respondents from the Deaths at Constantiaberg (CD) category.

In order to facilitate an easy interpretation of data presented, use has been made of visual representations of the data gathered. The researcher has used pie charts, bar graphs (including stacked bar graphs), histograms and frequency tables to present summarised information.

4.2 Response rate

As discussed in Chapter Three, response rates to postal questionnaires are notoriously low with return rates of up to 30% being common where reminders and incentives to respond are not utilised (Delport in de Vos et al, 2010). The risk of a small sample size was acknowledged by the researcher, who undertook the study knowing that reminders could not be sent when responses were anonymous, so that it was impossible to know who had returned a questionnaire and who had not. Of the 204 questionnaires dispatched, 15 were returned with an incorrect address or an unknown addressee. One hundred and eighty nine questionnaires were delivered.

The questionnaire requested that recipients return blank questionnaires if they felt uncomfortable, unable or unwilling to complete the task. Five questionnaires were returned blank and are

counted as Refusals to Participate. One questionnaire indicated that the death had occurred in a hospital other than the Constantiaberg Mediclinic, and although the questionnaire was complete, the response was excluded from the study as it did not fit the criteria in terms of place of death. Thirty four questionnaires for Home Deaths (HD) and 24 for Deaths at Constantiaberg (CD) were received, which combined with the blank returned questionnaires and the excluded return (on basis of place of death) provide a total number of 64 returned questionnaires, giving a response rate of 33.9%.

Suggestions about why the response rate for this study is higher than the 30% the literature suggests it might be:

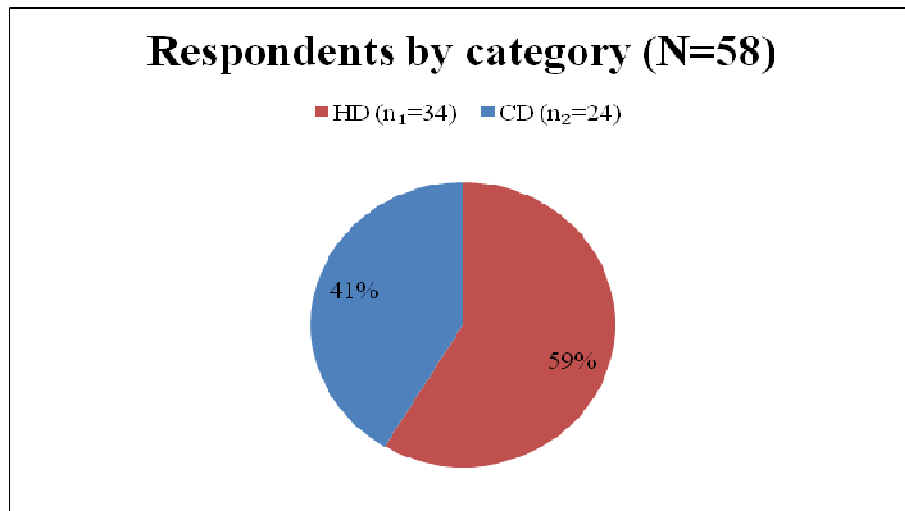
- the very personal and intimate nature of the questionnaire, providing an opportunity for reflection
- an altruistic desire on the part of participants to help improve care levels for future patients
- a need for catharsis
- recollection of a personal connection with the researcher who may have worked with the respondent during the patient's illness.

Although not directly related to the response rate, the researcher noted that several respondents added comments to their questionnaires, supporting the observation that the completion of the questionnaire may have offered people time to consider their experiences and to process some of their emotions in this regard.

As this study focuses on respondents from the CD and HD categories, the sample size will hereafter be taken as the total of 58, comprising 34 HD and 24 CD responses. Because there is an uneven number of responses from people who experience Home Deaths (HD) and Deaths at Constantiaberg Mediclinic (CD) and rather than eliminate respondents from the HD category to equalise numbers in each category, the researcher has worked with percentage representations in discussions where the responses in the categories are compared.

The chart below provides a graphical representation of the number of respondents from each category.

Chart One - Respondents by category



4.3 Basic demographic information

The questionnaire was designed to obtain some basic demographic information as it related to the respondent's relationship to the deceased patient, rather than an in-depth examination of socio-economic features. The information in this section provides an overview of the information gathered and assists in providing a context to the responses that followed later in the questionnaire.

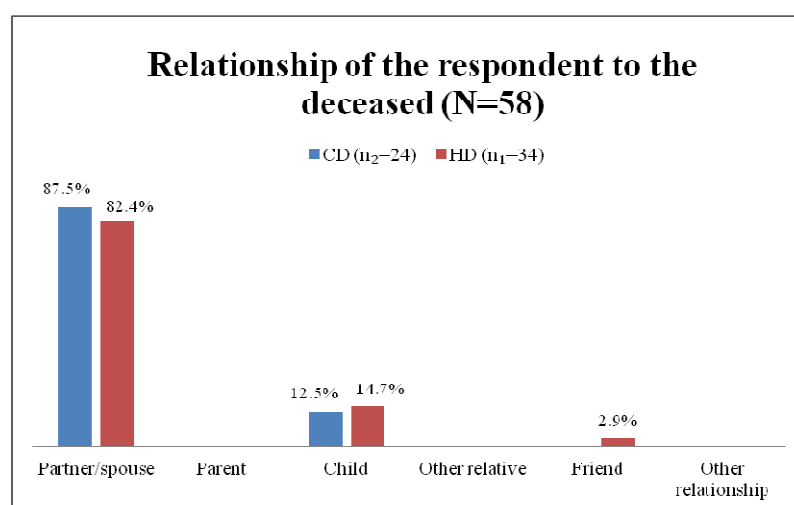
Although the returned questionnaires did not require identification from respondents, several chose to place their home address on the return side of the envelope used for posting. A brief perusal of these indicated that respondents were from a variety of residential areas in the southern Cape Peninsula area.

4.3.1 Relationship of respondent to deceased

The questionnaires were posted to people who were named at time of first registration with the GVI Oncology practice as being Next of Kin. As the population from which the respondents were drawn is one of mature adults, it is not unexpected that the majority of respondents (84.5%)

were spouses or partners of the deceased. A total of 49 people described themselves as being the Partner or Spouse of the deceased, in response to Question One, with an additional 8 checking the Child category on the response list. There was one person who checked the Friend category and no questionnaires were completed by the Parent of the deceased, or by anyone fitting the Other Relationship category.

Chart Two – Relationship of respondent to the deceased

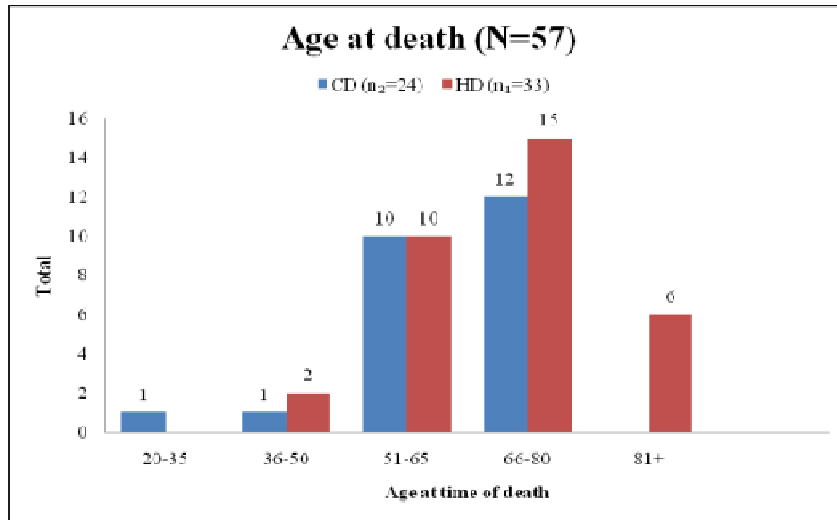


The bar graph above clearly indicates that the majority of respondents in both categories were spouses or partners of the deceased. This fact will be further explored later on in this section when the role of spouses as Informal Carers is discussed.

4.3.2 Age of deceased

The age of the person at time of death was the focus of Question Two and was analysed according to Place of Death (POD), as well as being broadly categorised into age groups, for simpler viewing and interpretation. One respondent did not indicate an age for the decedent, making the sample size N=57 for this section of information. The histogram below shows the distribution of ages for the deceased, comparing the HD and CD totals.

Chart Three – Age at death



More detailed analysis of the information has been undertaken to review gender and age, and to present more specific information. The overall range of ages was 57 years, from 30 to 87 years across both the HD and CD categories.

Table Two – Age at death - average, median and mode

	Male (n=32)	Female (n=25)	Total (N=57)
Average age at death	69.24	63.5	67.12
Median	68	67	68
Mode	81	69	69

A comparison between the ages and genders of the deceased and their place of death is presented in the frequency table below:

Table Three – Age at Death – Place of Death and gender included

	Male (n=32)		Female (n=25)		Total (N=57)
	HD (n=19)	CD (n=13)	HD (n=14)	CD (n=11)	
Average age at death	71.73	65.85	66.5	66.5	67.12
Median	74	67.5	67.5	57	68
Mode	81	68	68	73	69

This study specifically focused on an adult population, so that no questionnaires were sent to addresses where the deceased had been under the age of 20. Cancer as a group of diseases is known to be a condition that increases in incidence with advancing age (Parkin et al 2005), so can be described as a disease of the elderly. The average age at death in this study was 67.12 years, which supports this fact.

The male patients are noted to be older than the female patients on average, at death. This observation is particularly remarkable in comparing the average age of men dying at home, with the other averages – this figure is more than five percent higher than the other averages. The same sub-group (men dying at home), also has a higher median and a higher modal age. The researcher suggests that this may be accounted for by social and familial structures that may be better placed and prepared to care for the elderly dying man in the home. From personal observation, spouses of men tend to be younger, and female partners are socialised to assume and manage a caring role.

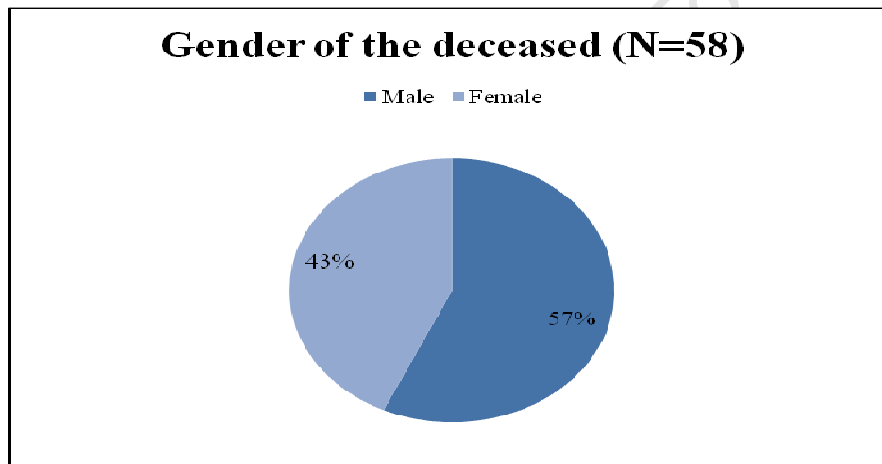
In contrast to the older age of men dying at home, women dying in hospital have the lowest median age of all sub-groups (57 years). This too may reflect on social and familial situations where male partners to women in this age group could still be in employment and hence less

available to provide care themselves at home (Cain et al, 2004). The existence of social support in facilitating a home death for women was noted in the Literature Review and is echoed in this finding (Izquierdo-Porrera et al, 2011).

4.3.3 Gender of deceased

The overall percentage of male deaths, including both categories is 56.9% and that of female deaths was 43.1% which is effectively illustrated in the pie chart below (with percentages rounded off):

Chart Four – Gender of the deceased



The gender of the deceased was recorded in Question Three and is summarised in the frequency table below, including the separation of genders according to place of death.

Table Four – Place of Death and gender

	Male		Female		Total
	Number	% age	Number	% age	
Home Death	20	58.8%	14	41.2%	34
Constantiaberg Death	13	54.2%	11	45.8%	24
Totals	33		25		58

The total number of male compared with female deaths reveals a higher number of male (57%) than female (43%) deaths and reflects the global tendency for higher male than female mortality due to cancer (Parkin et al, 2005).

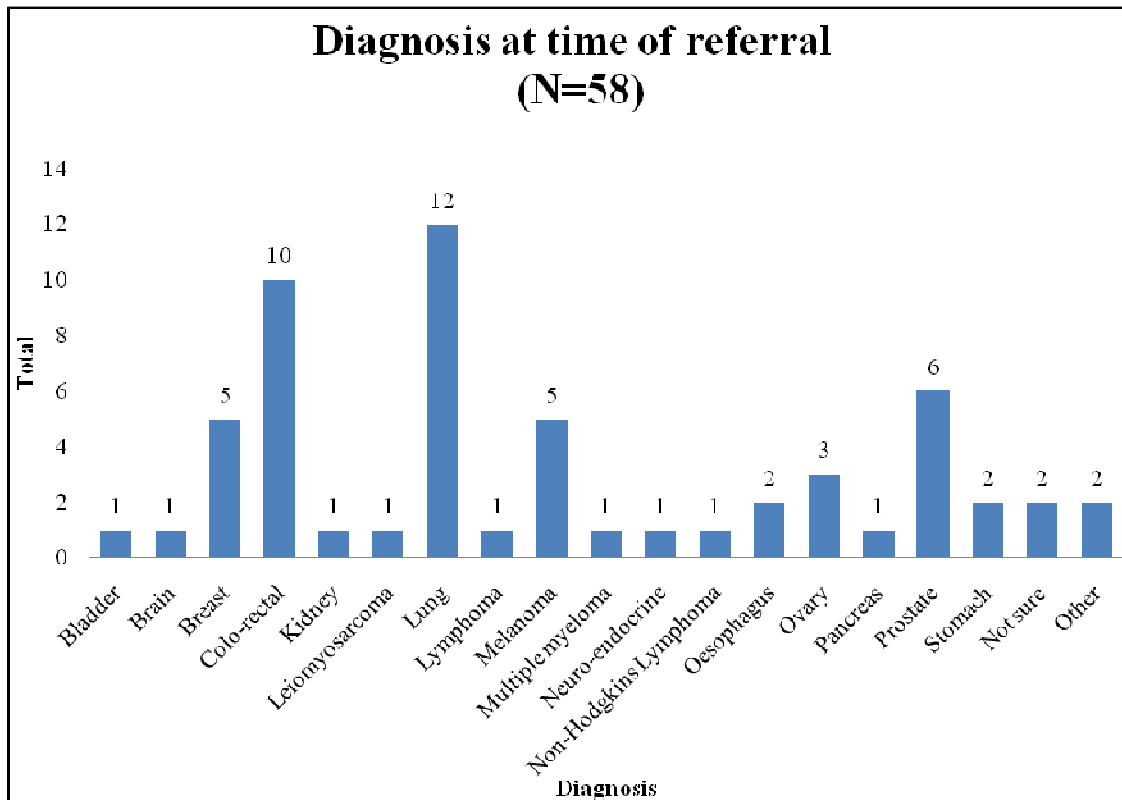
In both the HD and CD categories, more male than female deaths are noted, although the difference between gender distributions is higher in the Home Deaths category, with nearly 60% of the people who died at home being male. This fact may link with the observations made previously about Age and Place of Death.

4.3.4 Primary site of deceased's cancer

The GVI Oncology unit in this study has, as its focus, work with solid tumours, and therefore does not often have referrals of patients with haematological cancers such as leukaemia and lymphoma. The distribution of diagnoses of the primary site of the deceased's cancer features lung cancer as the most common diagnosis in this study and coincides with the fact that this cancer is the most commonly occurring cancer globally (Parkin et al, 2005; Jemal et al, 2011). Cancer of the colon and rectum, breast and prostate also have a high incidence rate (Parkin et al, 2005; Jemal et al, 2011), as was discussed in Chapter One and is reflected in the results indicated below.

Question Four required respondents to indicate where they believed the primary cancer site had been. It is general practice for the oncologist to ensure that any patient understands their diagnosis when initially referred, but there are times when the patient may not convey this information accurately to family members, hence the provision of choices for the respondents who were able to select from a list of ten commonly occurring cancer diagnoses, and were given the additional options of Not Sure and Other as categories. Fifty four of the respondents provided a total of 17 different diagnoses. Two respondents chose the Not Sure option and an additional two selected the Other option but did not specify what the diagnosis had been. This data is presented in an alphabetically-arranged histogram below:

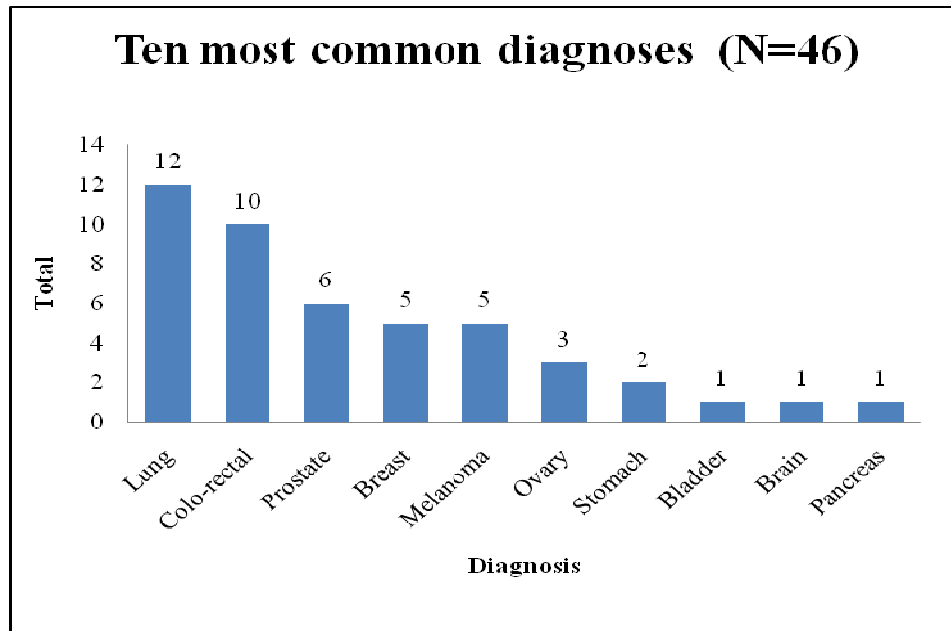
Chart Five – Diagnosis at time of referral



The fact that respondents appeared well informed about the patient's primary diagnosis suggests that, in general, there was some sharing and intimacy between the deceased and the respondent in terms of medical details. Some of the additional diagnoses offered by the respondents are less-commonly occurring cancers, with technical names to remember, again substantiating the observation that respondents were informed about and were involved in the patient's medical care.

When the additional diagnoses offered by respondents in the Other and Not Sure categories are excluded, and the data is limited to the ten diagnoses originally offered, the distribution of major diagnoses is clearer, and represents 46 patients.

Chart Six – Ten most common diagnoses



In descending order, this study had as its five largest diagnostic groups of lung cancer, then colo-rectal cancer, followed by prostate cancer and then breast cancer and melanoma. The profile of diagnoses encountered in this study reflects the more First World lifestyles of patients as opposed to a more Developing World profile that is encountered more broadly in Africa, where cervical and breast cancer have the highest incidence rates along with a growing number of people with HIV-related Kaposi's sarcoma (Parkin et al, 2008).

As this study does not specifically explore the symptoms experienced by patients prior to their death, it would be speculative to draw any conclusions about physical needs or care challenges facing those caring for patients. While it is understandable that different cancer diagnoses may hold differing trajectories (or symptom clusters) in terms of the dying process, this discussion is beyond the realm of the current study. In the section of the questionnaire that reviews the dying person's last 24 hours of life, there are two statements with direct reference to physical management, namely attending to pain control and the management of other physical symptoms (Questions 22 and 23). These will be discussed in Section 4.5.

4.3.5 Place of Death

The responses to Question Five contribute towards addressing the first of the Research Questions namely – “Where did patients from a private oncology unit die during the period 01 January 2008 – 31 October 2010?” As explained in Chapter Three, the researcher had a particular interest in deaths that occurred at home and under the care of a GVI oncologist in the ward at Constantiaberg Mediclinic in Plumstead. Deaths in other venues were excluded to allow for a comparison between the experiences of respondents from each of the HD and CD categories.

Chart One in the earlier part of this chapter presents a graphical illustration of the comparison between the number of respondents from each of the Home Death and Constantiaberg Death categories. The two categories used in the current study represent a portion of the total number of deaths recorded for patients of the GVI Constantiaberg Unit, and constitute the sample population for this study. When expressed as a percentage from eligible responses, a higher number was returned by people who had experienced death at home, with 59% of the total responses. This may suggest that HD respondents felt they had more to contribute, or were possibly proud of their role in providing home care, and may have been more comfortable sharing their experiences.

Based on secondary data gathered from GVI Constantiaberg Unit records as part of the preparations for this study, the researcher established that during the specified time frame 43.7% of all patients died at home and 26.9% dying in Constantiaberg Mediclinic under the care of the oncologist. The remaining 29.4% of patients known to have died did so in other places such as Frail Care facilities, other hospitals or in the St Luke’s Hospice in-patient unit.

In comparison with Place of Death studies conducted in other Western countries (Davies et al, 2006; Grunier et al, 2007; Agar et al, 2008), the figures in this study indicate a higher proportion of home deaths than hospital deaths, which may reflect on the lack of in-patient care facilities in the Cape Town community for terminally ill patients.

Whilst it is interesting to compare POD figures with those of other centres in Western countries, it is important to remember that this sample population in the southern suburbs of Cape Town

exists in a different socio-cultural setting to countries such as the United States, Britain, Scandinavia or Australia where community and Palliative Care are more formally established and more readily available to the terminally ill cancer patient and their family. Despite the presence or absence of locally generated figures about place of cancer-related deaths in this country, there concern that death should ideally take place in one's home environment, or in the place of the patient's choosing as an indication of patient autonomy was discussed in the Literature Review. This desire is noted in Section 4.6.2 in this chapter amongst the components of a Good Death provided by respondents.

4.3.6 Number of months since death

Due to the anonymous nature of the response sheets, it is not possible to calculate what percentage of respondents from each time category returned their questionnaires. Apart from providing the information requested, many respondents added the day of the week, or time of day on which the death occurred. Attention to detail in this manner suggests that details about a significant death are remembered and perhaps treasured in the story of an individual's loss. Although this additional detail was not requested, and the question itself was framed with the intention of making it non-threatening for those who could not recall the detail, there appears to be significance attached to the date by certain of the respondents. The majority of the combined responses were from people whose loss was 30 to 36 months previously, which may indicate that after more than two years, people may feel more comfortable reflecting on their experiences and observations.

There were no non-responders to this question and several people added additional information in their response. The data containing the Number of Months since Death was batched into the number of months since the death, and is summarised in tabular form:

Table Five: Number of months since death

	HD (n₁=34)	CD (n₂=24)	Total (N=58)
12 to 17 months	4	9	13
18 to 23 months	6	6	12

24 to 29 months	6	2	8
30 to 36 months	12	3	15
More than 36 months	6	4	10
Totals	34	24	58

The largest single group of respondents from the HD category (35.3%) were three to three and a half years post-bereavement, whereas the largest group of respondents in the CD category (37.5%) experienced their bereavement one to one and a half years ago. In a similarly contrasting way, 29.4% of the HD responders and 62.5% of the CD responders reported the death was less than two years prior to completing the questionnaire. The death took place more than two years prior to the questionnaire for 70.6% of the HD and 37.5% of the CD responders.

It is difficult to suggest why there was a difference between the two categories, except to respectfully and speculatively wonder if the respondents who were involved in a death at home (HD) had a greater need to participate in this study, even more than two full years after their bereavement. The researcher would further suggest that people who experienced a more recent (less than two years ago) death in the hospital setting (CD) may have had a stronger need to review their observations through the vehicle of the questionnaire, particularly if they had found the experience distressing or felt unprepared for the death – if this were the case, the answering of the questionnaire may in some way have served as a means of reflection and perhaps of letting-go of troubled or difficult memories.

The issue of accuracy of recall after a death has been addressed in work done with bereaved family members, and it is suggested that recollection can still provide useful information as long as seven years after the death (Krajnik et al, 2008). Whilst the accuracy of the issue of date of death is not being called to question here, concerns have been expressed about aspects of memory and the impact of bereavement on recall, as are outlined in Addington-Hall and McPherson's (2001) work. These authors state that all personal memories are contextual and are influenced by emotional states, but remain valuable sources of information when the deceased

subject is (obviously) unable to contribute to the discussion (Addington-Hall and McPherson, 2001).

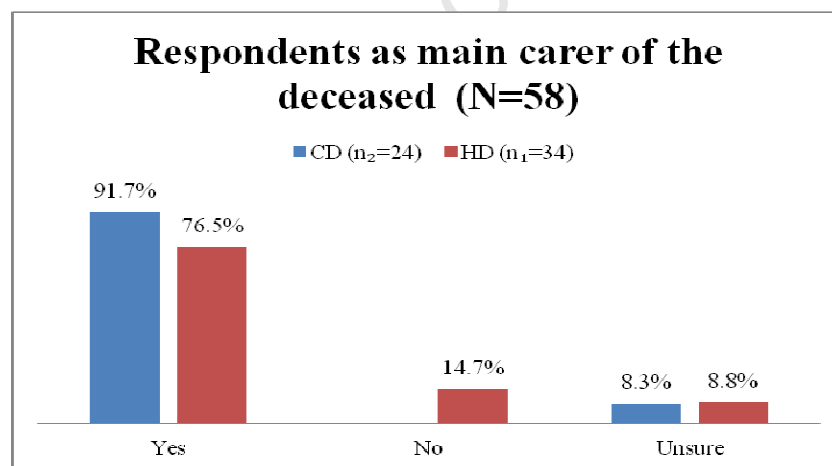
4.3.7 Caregiving information

Questions Seven and Eight asked for reflection on the role of caregiver for the dying person. In Question Seven the respondent was asked if they considered themselves the primary caregiver for the deceased, with a choice of Yes, No or Unsure options. Question Eight then enquired whether there was additional paid assistance for the dying person.

4.3.7.1 Respondents' role as main carer

The majority of respondents saw themselves as being the Main Carer for the dying person, with an additional five stating they were not the Main Carer, and a further five stating they were Unsure about their role. The comparison between HD and CD responses is represented below:

Chart Seven – Respondents as main carer of the deceased



When combined with details about the relationship of the respondent to the patient, it is apparent that the majority of partners or spouses were in fact the carer of the patient. This burden of being the informal carer to a person with a terminal illness is documented (Cain et al, 2004; Rokach et al, 2007; Andersson, Ekwall, Hallberg and Edberg, 2010). The partner or spouse may find themselves trying to run a household whilst simultaneously managing care, medical

appointments or arrangements as well as other duties (Rokach et al, 2007; Andersson et al, 2010). The caring role may become extended to a round the clock duty, with potential for physical and emotional burn out (Glajchen, 2004).

It is therefore suggested that the higher figure of 91.7% partner/spouse/carers in the CD category, may account in part for the patient’s admission to hospital. The HD category has a lower figure of 76.5% in the spouse/partner/carer role, suggesting that the spouse/partner had additional assistance with caring, which potentially enabled the patient to remain in the home for the terminal stage of the illness.

4.3.7.2 Employment of additional help

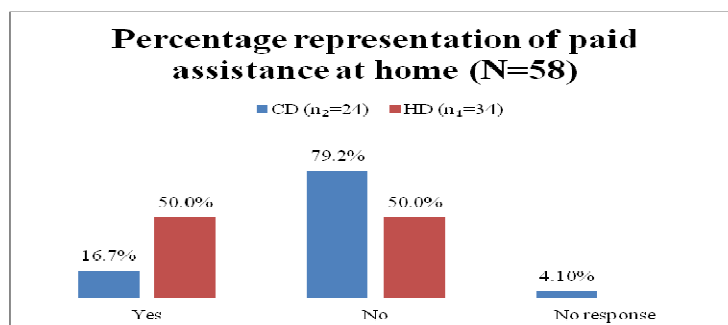
An equal number of people who died at home had paid help, compared with those who did not (n=17). Of those who died in hospital, the majority of patients (n=19) did not have paid assistance at home prior to admission. Four of the patients who died in hospital did have paid assistance. This question was answered by all except one respondent.

Table Six – Employment of additional help

	HD (n₁=34)	CD (n₂=24)	Total (N=58)
Yes	17	4	21
No	17	19	34
No response	0	1	1
Total	34	24	58

In percentage terms, the discrepancies are easier to observe in graphical form:.

Chart Eight – Percentage representation of paid assistance at home



Although the question did not enquire what type of assistance was employed, there is an implication in terms of cost to patient and family, as well as the shared load of providing care for the patient. The problem of the cost of caring for a terminally ill person is explored in the Literature Review and the complexity of potential financial outlay is detailed by Tilden et al (2004). In South Africa, members of medical aids (private medical insurance companies) may be able to approach the medical aid for financial assistance with providing home care to the terminally ill patient in lieu of hospitalisation (Manicom, 2011). This process is arduous in most situations, with medical aids requiring a letter of motivation from the treating oncologist, an assessment and a quote for services required from a registered nursing practitioner, and then a review of the application by an assessment panel at the medical aid offices. Certain medical aids will provide cover according to the tier or level within the scheme the medical aid member occupies. Certain medical aids provide no cover for this type of care at all, and others are extremely specific about the “terminal” nature of the illness, making the timing of such an application extremely difficult.

If a family or individual is able to pay for care from a Nursing Assistant (with a practice number) at home, on a 24-hour basis, the costs involved may be upwards of R8 000 – R12 000 per month, which is prohibitive for many people.

Hence, paid nursing services at home are an expensive addition to a household’s budget (Wood and Fox, 2005; Manicom, 2011). St Luke’s Hospice is the main service provider of domiciliary palliative care in Cape Town and in the southern suburbs in particular. This organisation has a network of nursing sisters who are able to consult, advise and support patients and families, but is unable to render daily care to patients at home. Certain medical aids will cover costs for services from the Hospice, and as a Not-for-Profit organisation, services are not withheld from patients if there is no medical aid cover or other means to pay. Even with regular visits and support from St Luke’s Hospice, the family and friends of the dying patient remain primarily responsible for that person’s care at home.

In the light of this paucity of practical support for the carers of terminally ill people in the community, it is not surprising that the figure for paid assistance at home in the CD category is as low as 16.7%. Nearly 80% (79.2%) of the patients in this study who died in the Constantiaberg Mediclinic did not have paid-for nursing care at home, placing the responsibility completely on the shoulders of that person's social circle. Where the patient's illness had been protracted or the needs of the patient were substantial, it is easy to surmise that an element of caregiver burden (as discussed previously) may have contributed to the final hospital admission. When compared with the 50% of HD respondents who indicated that they did have paid-for assistance at home, it appears logical to conclude that the presence of some additional help in the home environment enabled families to care for the patient until death at home.

4.3.8 People present at moment of death

The final two questions in the first section of the questionnaire enquired about whether the deceased died on their own or with company. The following two questions were included to establish whether the deceased as alone at time of death or not, and who the witnesses or supporters may have been at that moment.

4.3.8.1 Anyone present at moment of death

Question Nine required a Yes, No or Unsure answer from respondents, with the following results reflected in a frequency table. From this table, it is apparent that the majority of decedents were not alone at the time of death. 91.7% of CDs were in the presence of at least one other person, with the figure for HDs being higher at 97.1%.

Table Seven – Was anyone present at the moment of death?

	HD (n₁=34)	CD (n₂=24)	Total (N=58)
Yes	33	22	55
No	1	0	1
Unsure	0	2	2
Totals	34	24	58

Question Nine is the first question in the questionnaire that links directly to previously established lists of preferences, or requirements for Good Death (Henwood, 1999; Kehl, 2006).

The contemporary Western tradition appears to require that people are not alone at time of death, and certain cultures may have prescriptions about social behaviour at the death bed, including who should be present if possible, and may even specify rituals in terms of physical contact, prayer or meditation, weeping or rending of clothes and so on. For respondents coming from such traditions, attendance at time of death of a loved one may have more significance than for others from different backgrounds. It is therefore important for medical professionals to be aware of cultural and religious observances or requirements around the time of death, which may prescribe who should be in attendance (Woof et al, 1998).

When viewed as a percentage, more than 90% of respondents from both categories stated that the dying person had not been alone at the time of death. This figure was higher for the HD category, where it would be logical to believe that the household could be more rapidly available if it were apparent that the patient was imminently dying. In a hospital ward situation, summoning family members urgently can be problematic, and ward staff are generally unable to sit exclusively with a person who appears to be in extremis. The staff in the particular ward at Constantiaberg Mediclinic will attempt to provide company for the dying person in the absence of friends or family members, but there are times when the patient does die unexpectedly or alone.

4.3.8.2 Details of persons present at moment of death

The final question in this section of basic data, Question Ten, enquired who had been present at the time of death if the respondent had replied in the affirmative to the previous question. Several options were presented with the intention of discretely acknowledging different cultural practices or observances.

Many respondents indicated that more than one person was present at the time of death, with spouses or life partners being present more frequently at time of death at home than in hospital (73.5% for HD and 62.5% for CD). Although the researcher did not request a head count of the number of people present at time of death, but rather required an indication of what groups of people were present, it is suggested that a hospital death may be viewed in some communities as

being a more public event, therefore allowing a greater number of people to be present at the time of death. By contrast, death at home may be seen by some as being a more private, intimate affair, with only immediate carers or loved ones present.

Table Eight below provides the list of people who were present at the death, with the total number of people present being excluded table as several people may have been in attendance, and this question enquired more about the nature of relationship between the people present and the dying patient, than a specific number of people present.

Table Eight – Details of people present at moment of death

Person present at death	CD	HD
Spouse or life partner	15	25
Parent	1	2
Child	8	13
Sibling	2	6
Other relative	6	7
Member of medical staff	5	11
Minister of religion	1	2
Friend	2	6

Of interest is the observation that proportionately, there was a greater number of medical staff in attendance at the time death for HDs than CDs. This appears counter-intuitive in the light of a hospital setting, but is possibly explained by the use of employed nursing help in 50% of the patients dying at home. The researcher suggests that where there was an informal caregiver, as well as a paid nurse, there would be a closer monitoring of the patient's condition and decline than in a busy acute care medical ward. It is also known that Hospice community sisters may be called to the patient's home at a terminal stage, particularly if there are distressing symptoms that require management, which may account further for the apparently high number (32.3%) of medical staff present during HDs. This active role of Hospice community sisters in the patient's dying process is an extension of the Palliative Care philosophy that requires not only physical support but psycho-social care for the dying and for the carers or family members (Callaway and

Ferris, 2007), supporting the concept of partnership in care and the key role of the Inter-Disciplinary team in providing this care (Schachter and Coyle, 1999; Crawford and Price, 2003).

4.4 Review of the last week of the dying person's life

In terms of the dying trajectory that was discussed in Chapter Two, the final week of a person's life with advanced cancer will frequently feature signs and symptoms of approaching death such as declining appetite, poor oral intake and possibly increasing confusion or drowsiness (Woof et al, 1998; Ellershaw and Ward, 2003). Ideally, the patient and family are made aware of this approaching dying process by professional staff members who may be in attendance at home or in hospital, which enables physical, psychological and spiritual preparation for the death itself. Sometimes the death occurs more suddenly than anticipated, making advance warning impossible, potentially leaving family members feeling bewildered, confused or angry following the death of the patient (Woof et al, 1998). This section of the questionnaire began the process of focusing the respondents' attention on the dying itself, including preparations for the dying process such as practical arrangements, and the availability of care.

In order to compare the two categories of responses without relying on totals from differing sample sizes (HD $n_1=34$; CD $n_2=24$), the researcher has made use of percentages in the charts that follow.

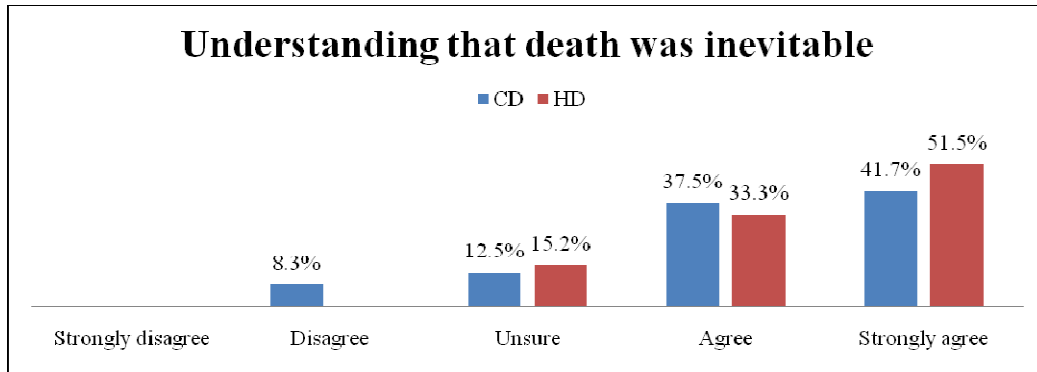
4.4.1 Understanding that death was inevitable

One respondent in the HD category did not answer this question, making the total responses $n_1=33$ for HD and $n_2=24$ for CD. No respondents strongly disagreed with this statement.

This question sets the tone for questions to follow, and gave the respondents the opportunity to consider how prepared they felt for the death of the patient. It enquired directly whether the respondents were aware of the imminence of death. In both categories of respondents, the majority were in agreement that they had understood the patient was dying. In terms of relationships and emotional coping, this understanding should have assisted the respondents with their own endings and subsequent grief (Grassi, 2007). Death was therefore an anticipated event for most of the respondents, as opposed to a sudden and unexpected death. Acknowledgement

and preparation for approaching death is known as anticipatory grief (Grassi, 2007) and has been discussed in Chapter Two.

Chart Nine – Understanding that death was inevitable

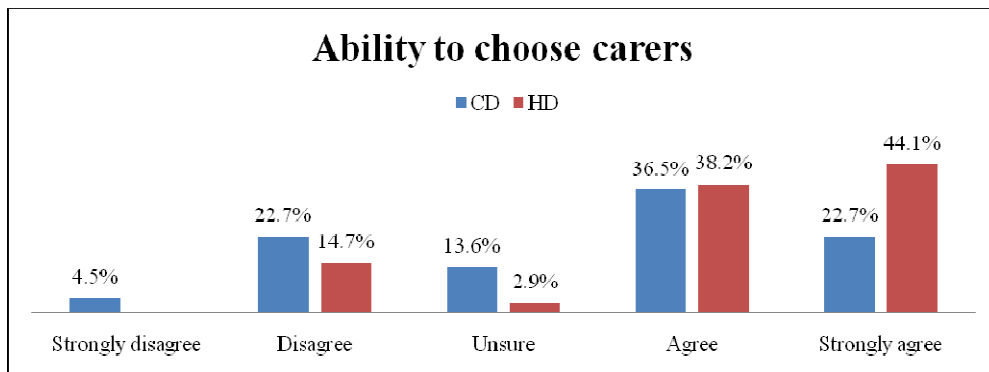


Although Chart Nine clearly indicates that most of the respondents had an awareness of the inevitability of the patient’s death, it is possible that some of the deaths experienced were as a result of a sudden deterioration in the patient’s condition, and were hence unexpected. It is also possible that some of the respondents were genuinely unaware of the severity of the patient’s condition, or utilised the defence mechanism of denial to avoid confronting their impending loss. This questionnaire was not designed to assess individual coping styles, and sought to record the perception of respondents who may or may not have understood that death was inevitable.

4.4.2 Ability to choose carers

Two people in the CD category did not answer this question, making the total responses $n_1=34$ for HD and $n_2=22$ for CD.

Chart Ten – Ability to choose arers



Question Twelve elicited a range of responses from strong disagreement to strong agreement about the choice or control the respondent had in selecting carers for the dying person. Most of the HD (82.3%) responders agreed that they had choice in this selection, whereas 59.2% of the CD respondents agreed. By contrast a total of 27.2% of the CD category replying that they disagreed that they had choice in who was involved in the caring.

The respondents in the CD category may have felt a lack of control about selecting carers in the hospital setting where patients and families are not involved in staffing choices. This powerlessness may have resulting in feelings of vulnerability for respondents, especially if there were concerns about competency or compassion levels of individual staff members.

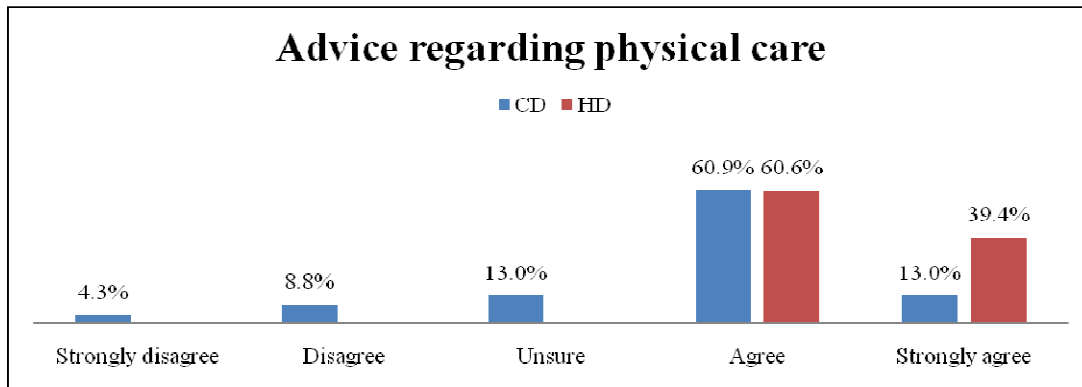
Underpinning these feelings may be caregiver stress as described in the Literature Review, which may include features of exhaustion, depression and social isolation (Cain et al, 2004; Glajchen, 2011). An additional observation regarding the CD respondents is the possibility that some of them may have believed there was no choice in terms of carers for the patients, simply because none were available to them at home, and in the hospital ward staffing is allocated, without patients or families being able to choose their individual staff members. Therefore any sense of independence or authority in terms of selecting carers may have been absent for the CD respondents.

In contrast, the HD respondents may have experienced a lower level of personal burden and responsibility by virtue of the fact that they felt they were able to choose carers, and as will be seen later in this section, many of the HD respondents had additional paid-for nursing help at home, broadening their sense of autonomy and choice.

4.4.3 Advice regarding physical care

One person from each of the HD and CD categories did not provide an answer, making the totals $n_1=33$ for HD and $n_2=23$ for CD.

Chart Eleven – Advice regarding physical care



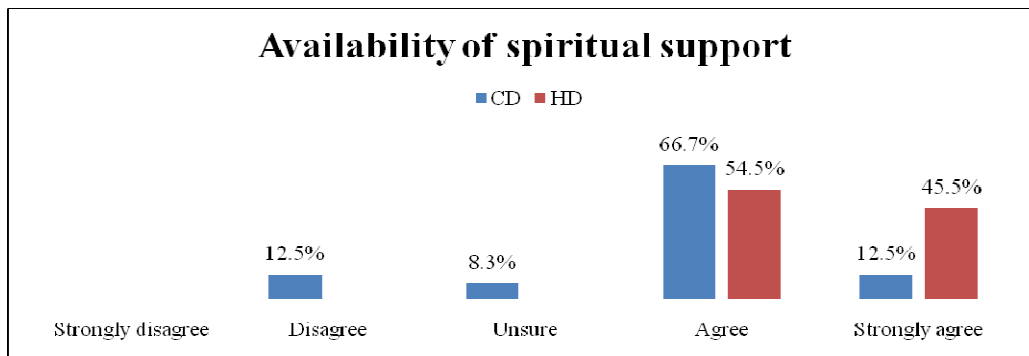
The HD respondents to this statement all indicated that they knew where to get advice regarding physical care for the patient, which suggests confidence and trust in the medical resources available. This agreement may also reflect on a sense of control on the part of the respondents, and possibly a shared load in terms of responsibility for caring.

By contrast, 13.1% of the CD respondents did not know where to get advice about managing physical care and a further 13.0% were unsure about where to get such advice. Studies of the needs of Informal Carers have indicated that there is a commonly reported need for information about the anticipated prognosis of the patient, the probable course of the illness, and practical guidance regarding various aspects of home care (Mangan et al, 2003). Additionally, researchers have found that there is a need for some certainty in terms of access to and appropriate use of resources, which assists families to feel a better sense of control in their role as carers (Friedrichsen, 2003; Cain et al, 2004). This lack of certainty may in part account for the terminal hospital admission of the patient. Whilst it is not possible to prepare every family for every eventuality, information and access to practical support has been found to reduce the anxiety of Informal Carers of the dying patient (Friedrichsen, 2003; Cain et al, 2004). In the situation where caring for the terminally ill person was a new and unfamiliar task for respondents or their family members, uncertainty about community and professional resources may also have contributed to feelings of anxiety and distress.

4.4.4 Availability of spiritual support

There was one non-response from the HD category, giving totals of $n_1=33$ for HD and $n_2=24$ for CD. No respondents strongly disagreed with this statement.

Chart Twelve – Availability of spiritual support



All of the HD respondents agreed that they had access to spiritual support, while 12.5% of the CD group did not feel they had spiritual support available. This may be a reflection on the clinical environment that is an acute care hospital, although the Constantiaberg Mediclinic does have a selection of religious leaders available to provide prayer and support should this be required by patients or by families. It is possible that respondents were either not aware of this service, were not sufficiently comfortable to ask for, or did not think about requesting spiritual support during the patient's stay in the ward. A further suggestion regarding the respondents from the CD category who did not experience spiritual support is that with the patient being in hospital, the respondent and patient may have felt isolated or removed from their spiritual base or religious community, and hence may have perceived a lack of support.

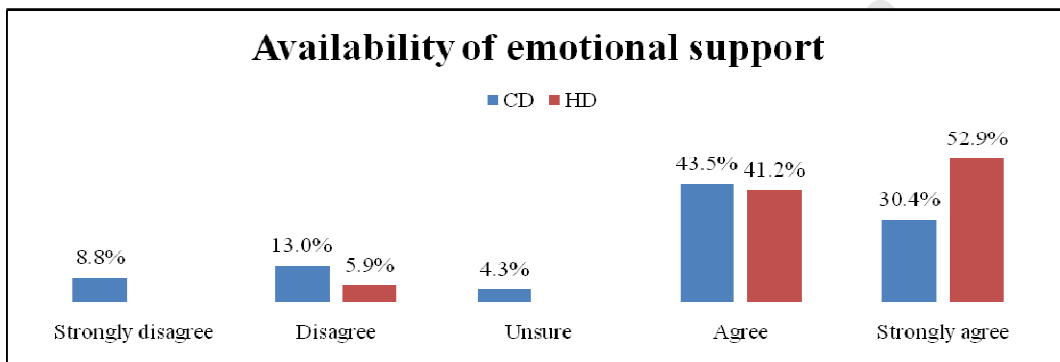
The presence of spiritual support for the dying person and for the immediate family or carers is widely documented as being an important aspect in end of life care (Emanuel & Emanuel, 1998; Henwood, 1999; Steinhauser et al, 2000; Walter, 2003; Kehl, 2006). It is regarded as being a core element of Palliative Care (Schachter and Coyle, 2009; Tanchel, 2003; Callaway and Ferris, 2007) alongside the psycho-social care which may be offered by a variety of professionals, including social workers (Monroe, 2004). Religious practitioners and spiritual counsellors are

actively included in Palliative Care teams (Crawford and Price, 2003), and play a vital role in the work of St Luke’s Hospice, which serves all religions despite its Christian-sounding name.

4.4.5 Availability of emotional support

One respondent from the CD category did not provide a response, giving figures for total number of responders for HD $n_1=34$ and CD $n_2=23$.

Chart Thirteen – Availability of emotional support



Once more, the majority of the HD respondents felt supported in this regard, and the response from the CD category was more mixed, with over a quarter of the respondents feeling Unsure or not in agreement that emotional support was available. This may reflect on a sense of emotional isolation prior to the hospitalisation of the patient, or may be a response to the hospital experience itself which in some cases can be a lengthy and uncertain period during the patient’s illness. There is also the possibility that some of the respondents in the CD category did not know how to access or request emotional support. Here it should be noted that social work services from the GVI Oncology unit are only available during office hours.

Over and above these factors, the hospital environment with its clinical focus and frequent staff changes can result in a sense of bewilderment and anxiety for patient and for family members (Costello, 2006). It is the general practice of the oncologists in this study to conduct a ward round once a day, and not to return to the ward unless there is a new development. When there is no family member present at the time of the ward round, and there is concern about

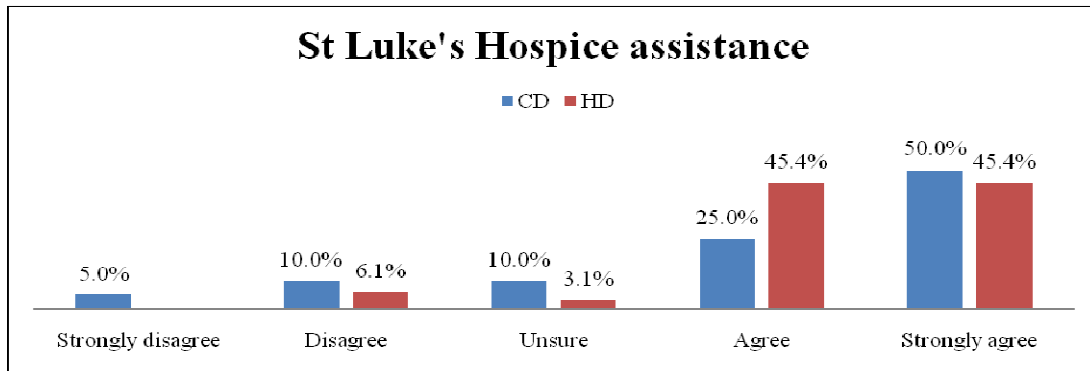
communications with family, the oncology nurse or social worker is tasked with daily phone calls to the family to update them. The oncologist is reliant on feedback from team members about individual patient's condition during the day, and will respond using telephonic orders, or assistance from the team's nursing or social work staff. The family and patient may have had expectations beyond this that were not articulated and therefore were not addressed, potentially leading to a sense of dissatisfaction or to feeling emotionally un-attended.

Although different in nature to spiritual support, emotional support is also considered to be extremely important for the dying person and those around them in terms of ensuring a Good Death (Emanuel and Emanuel, 1998; Henwood, 1999; Steihauser et al, 2000; Walter, 2003; Kehl, 2006). The arena of emotional support for the family and carers of the dying person is an aspect of care that may fall to the social worker whether the patient is at home or is an in-patient in hospital (Monroe, 2004; Hebert et al, 2008; Glajchen, 2011). It has been noted that caregivers are at risk for feeling overwhelmed or over-burdened by their role (Given et al, 2001; Cain et al, 2004) or of developing depressive symptoms (Rivera, 2009). The health care team has an important role in reducing psychological risk in family members and potentially improving emotional outcomes by providing individualised support to the patient and family members (Given et al, 2001).

4.4.6 St Luke's Hospice assistance

Four respondents from the CD category and one from the HD category did not respond to this question, giving totals of $n_1=33$ for HD and $n_2=20$ for CD. This question, together with Question 18 evoked the lowest number of responses in this section of the questionnaire. This may have been because not all respondents were familiar with the work of St Luke's Hospice in the community, or it is possible that the non-responders were not aware at the time of the patient's illness that St Luke's assistance may have been available to the patient and family.

Chart Fourteen – St Luke’s Hospice assistance



Question Sixteen was included to provide some insight into the usage of the local Hospice service by the patients represented by their respondents. In general terms, the St Luke’s Hospice is able to provide palliative care services to most areas in the southern suburbs of Cape Town. However, their referral procedure precludes emergency or last-minute referrals, requiring that patients are registered with the Hospice before services can commence. This administrative requirement is understandable to those in the field, but may be disappointing or frustrating for those who have not timeously requested assistance. For many patients and families the mere mention of a Hospice referral requires an acknowledgement that death is inevitable, and this may be an uncomfortable and unwelcome topic although such honest conversations are essential to good Palliative Care. As a result, late referral to Hospice services is a common phenomenon (Grunier et al, 2007) and is not limited to the Cape Town context alone. The GVI Oncology practice in this study routinely tries to ensure early referrals for Hospice support, but ultimately these referrals require patient and family consent, which is not always forthcoming.

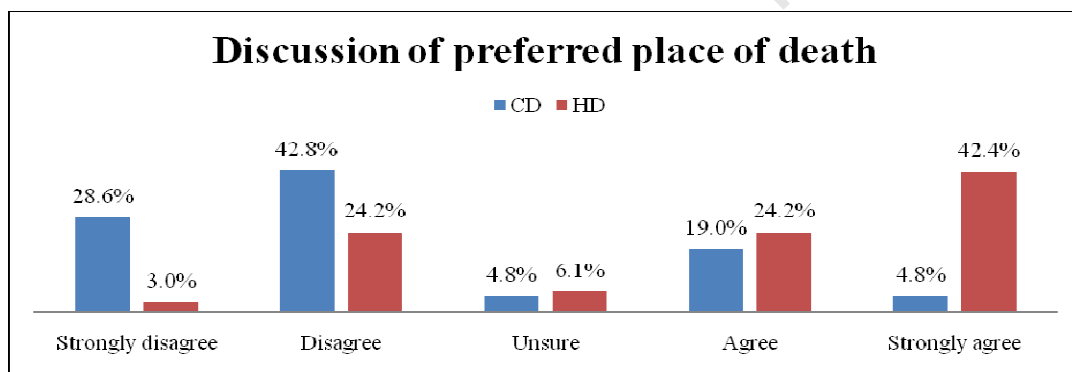
The majority of respondents in both categories believed Hospice assistance was available. A total of 25% of the CD respondents responded that they were Unsure, or did not agree that such assistance was available. This response may again point to the need for a hospital admission rather than home care in the terminal stage, as those in the CD category may have felt unprepared and insufficiently supported at home to manage the dying process there.

The researcher notes that there was greater agreement about St Luke’s Hospice availability amongst HD respondents, many of whom would have benefitted from the services of this organisation. It is suggested that support from this Hospice, together with additional paid help (as previously discussed) will have greatly contributed to ensuring a death at home for the patient.

4.4.7 Discussion of preferred place of death

One respondent from the HD category and three from the CD category did not enter a response to Question 17. The total number of respondents were therefore $n_1=33$ for HD and $n_2=21$ for CD.

Chart Fifteen – Discussion of preferred place of death



Two thirds of the HD respondents agreed that a discussion around place of death had taken place, while 71.4% of the CD category disagreed with this statement.

Initiating a conversation about preferred place of care and preferred place of death is not easy or comfortable for many patients and their carers, and may be avoided as being a topic that is perceived to be too emotional. This avoidance has been observed in literature (Mangan et al, 2003) with the consequence that without discussion about dying, it is difficult for family members or patients to actually plan for care, or to have a sense of control of the dying process. When there is no prior discussion, it may be difficult for family members to make decisions about where and how to care for the dying patient, especially in a moment of crisis or when there is a sudden change in that patient’s condition. This lack of clarity may leave family members

feeling ambivalent about a hospital admission, especially if that admission was immediately prior to the patient's death.

The researcher suggests from her own clinical experience that families may prefer to focus on discussions around care and resources to facilitate care, rather than focus on questions about place of death. It is understandable that conversations of this nature may be uncomfortable, but can be initiated or facilitated by Hospice staff, or the social worker, or the oncologist themselves (Agar et al, 2008) and should form part of the doctor's advance care planning with the patient (Degenholtz et al, 2004). Questions about preferred Place of Death could include: Where would you prefer to die? How can we make that happen? What would be an acceptable alternative if this is not possible? After a professional team member has had this discussion with the patient and family members, the content or at least decisions should be noted in the patient's medical records.

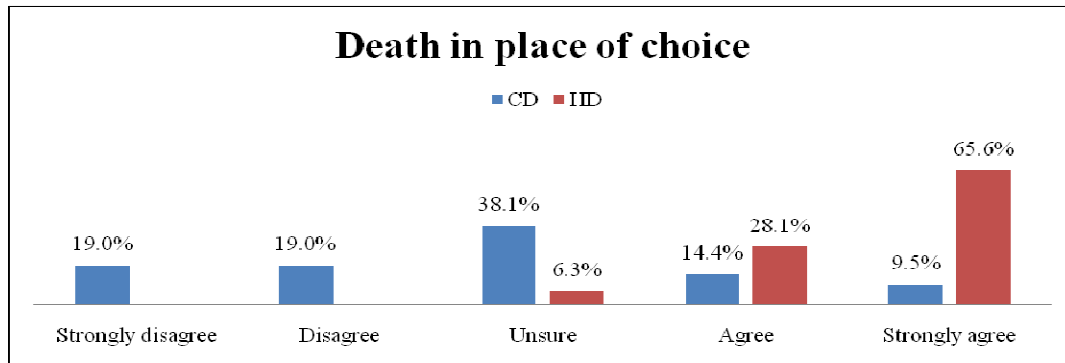
In terms of planning for end-of-life care, researchers suggest that the patient be given as much autonomy in the process as possible, taking into consideration the patient's mental state and capacity to make informed decisions, the ability of the carers to provide the appropriate and a realistic review of resources available (Brazil et al, 2005; Wheatley and Baker, 2007; Agar et al, 2008).

4.4.8 Death in place of choice

Two respondents from the HD and three from the CD categories did not respond to this question, giving totals of $n_1=32$ for HD and $n_2=21$ for CD.

This question, together with Question 16 evoked the lowest number of responses in this section of the questionnaire. Place of Death is another concept that is considered important in terms of end of life care, and in ultimately ensuring a Good Death (Steinhauser et al, 2000; Kehl, 2006). This has been discussed previously in the Chapter Two and was referred to earlier in this chapter. While the physical location for death may be of importance in terms of comfort, privacy, available care and patient preference, the concept of discussing where a person chooses to die reflects on patient autonomy and their rights (McNamara, 2004; Wheatley and Baker, 2007).

Chart Sixteen – Death in place of choice



The responses to Question Eighteen link closely to those of the previous question. In general respondents who agreed that there had been a discussion about place of death also agreed that the person died in the place of their choice (HD 93.7% and CD 23.9%). In the CD category, many respondents (38.1%) were Unsure about whether this was the case or not which links to the previous question where the majority of CD respondents had not discussed possible POD so did not know where the patient would have liked to die – hence, they were not able to reply whether a hospital death was what the patient would have preferred or not.

Literature indicates that the place of care does not always guarantee that the dying person will in fact die in that same place (Bell et al, 2010), as there may be changing preferences over time (Agar et al, 2008), altering practical or care needs (Wheatley and Baker, 2007), or the informal caregiver's own physical and mental condition and ability to continue with the caring role (Brazil et al, 2005; Wheatley and Baker, 2007). The work of Australian authors Agar et al (2008) broaden the discussion to remind health care professionals that the actual Place of Death may not be a major concern to the dying person, and that their place of care is of more importance to them.

However, the researcher believes that for many bereaved family members, there is some comfort to be derived from believing that the patient died in the place of their choice, and that this may contribute towards their sense of it having been a Good Death. The period immediately preceding the patient's death may be eventful or calm, but the last hours of a person's life and the

perceptions of those witnessing the dying may remain in their memories for a long time (Wood and Fox, 2005).

The final stage of the patient’s life usually features physical signs that indicate the approaching death, as described in Chapter Two. The following section required respondents to attend more closely to the dying process in terms of relationship and comfort issues. Aspects of patient care, and the understanding by the respondent of the imminence of death may have contributed to the overall perception of the experience.

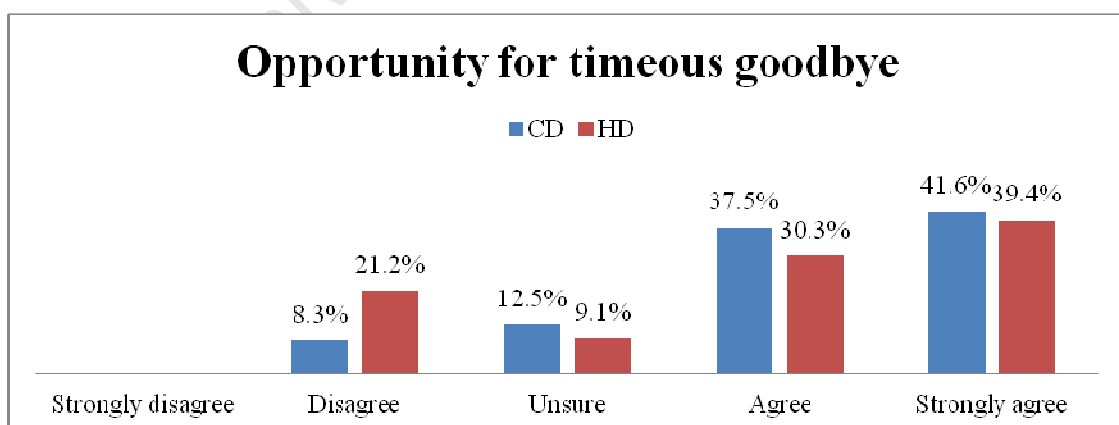
4.5 Review of the last 24 hours of the dying person’s life

This section of the questionnaire comprised statements which required an indication of agreement or disagreement, and two specific questions that necessitated free text responses.

4.5.1 Opportunity for timeous goodbye

One person in the HD category did not respond to this statement. The totals then for HD $n_1=33$, $CD_2=24$. No respondents strongly disagreed with this statement.

Chart Seventeen – Opportunity for timeous goodbye



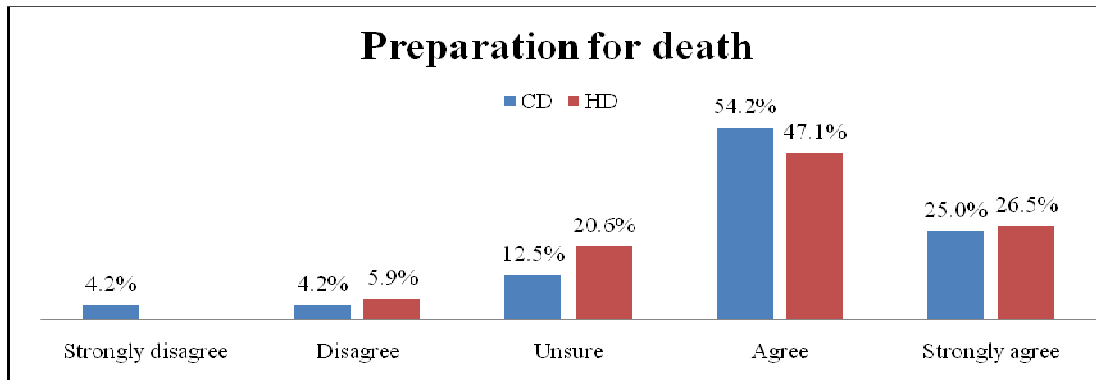
The statement in Question Nineteen relates again to preparedness for the death, and to the opportunity the respondents felt that they had for relationship completion. Most respondents in the both categories agreed that they had been able to say goodbye to the patient, with slightly higher percentages of CD respondents feeling prepared than those in the HD category. It is possible that the very presence of the patient in hospital in itself served to forewarn family members of possible impending death. By contrast, the task of caring for a person at home could have felt indeterminate to some respondents, with the result that they did not consciously say farewell to the patient. The act of saying goodbye (for the final time) to a loved one implies an understanding that the relationship is terminating. Death is the ultimate leave-taking, and grieving survivors may draw emotional comfort from the knowledge that they were able to say goodbye. The implementation of an Integrated Care Pathway, as discussed in the Literature Review provides the patient (if alert), and the family the opportunity to say farewell and potentially to complete any unfinished business prior to the death.

When there has been a sudden death, with little preparation or opportunity for farewells, there may be a protracted grieving period (Chochinov et al, 1998). Several features may be present in the grieving pattern of people who believe they have experienced a sudden death, and these may apply in certain cases where the death due to cancer happened sooner than was anticipated. Worden (2002) includes in these features the possibility of feelings of guilt, a sense of helplessness for the survivor, the potential for matters regarding unfinished business to contribute to regrets, and the need of the survivor to understand what happened or to make meaning of the loss.

4.5.2 Preparation for death

There was a complete response to this statement from all respondents, giving totals HD $n_1=34$ and CD $n_2=24$. None of the respondents strongly disagreed with the statement.

Chart Eighteen – Preparation for death



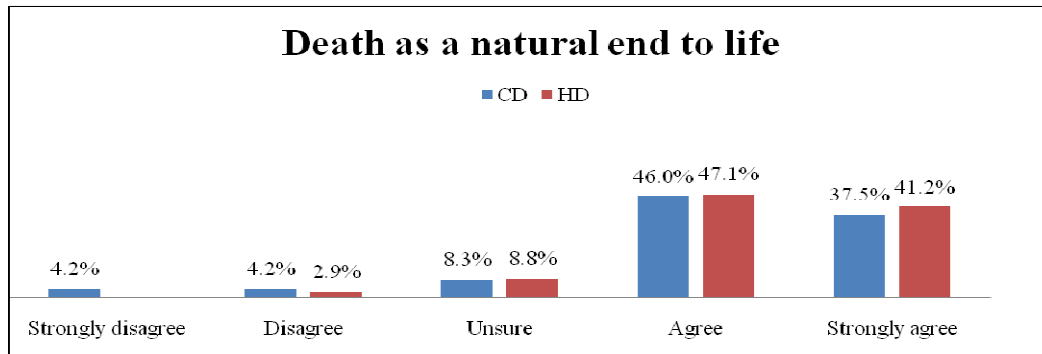
Nearly three quarters of both groups of respondents agreed with this statement – HD (73.6%) and CD (79.2%), with a smaller number indicating they were Unsure and a minority in each group responding that they did not feel prepared for the death of the patient. It is possible that people who agreed with the earlier statement regarding the inevitability of death, also agreed in this instance. Being aware of the impending death of the patient would have, for most respondents, have served as partial preparation for the loss. Worden (2002) describes the acceptance of the reality of the individual’s loss as being the first of several tasks in the mourning process, requiring intellectual and emotional acceptance of the loss.

Preparation for the death of the patient could have been interpreted to be at a practical, an emotional or informational level (Hebert et al, 2008). In terms of facing the loss of a significant relationship, the period prior to death may have given the respondents time for “intellectual preparation” (Chochinov et al, 1998:1018) and for the subsequent settling of personal or inter-personal conflicts with the hope of relationship completion. Psychologically, this time of preparation may be referred to as anticipatory grief which enables people to consider their own future life without the deceased, and allows for the development of new roles (for example decision making) (Hedlund and Clark, 2001).

4.5.3 Death as a natural end to life

This statement elicited a response from each respondent, giving totals HD $n_1=34$ and CD $n_2=24$.

Chart Nineteen – Death as a natural end to life



Before commenting on the responses to this statement, it is important to emphasise that this study focused on deaths occurring in the home, and in an acute care ward setting – none of the patients who died in this sample were cared for in High Care or Intensive Care units, and none of them would have been on artificial ventilation or life support prior to their death.

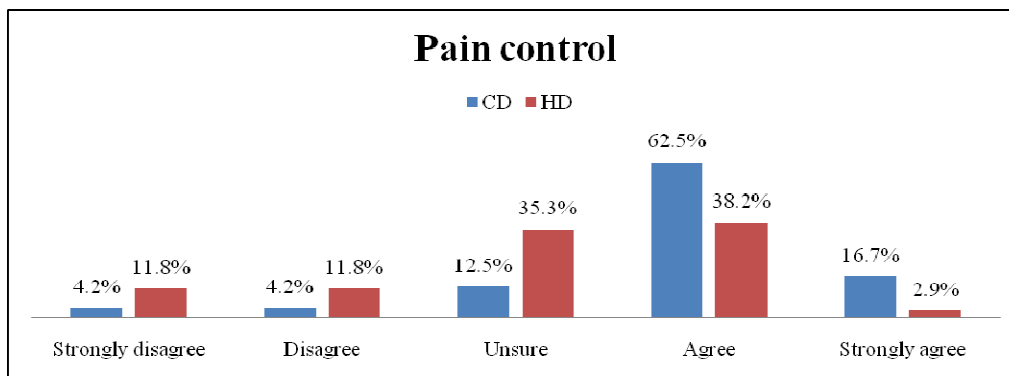
The intent of Question 21 was to establish whether respondents felt the process of the death to be appropriate in terms of timing and preparedness of the patient and the family members. Issues of patient autonomy and respect for the patient's and family's wishes may be raised through a statement such as this, and some respondents did offer additional comments on this topic. Most of the respondents in both categories were in agreement with this wherever the patient died statement (HD 88.3% and CD 83.5%), suggesting that the respondents had a sense of preparedness and of the inevitability of the death.

In her article about the concept of a Good Death, Karen Kehl (2006: 282) describes this aspect of dying as the "Appropriateness of death" and specifically refers to the lack of technology involved at time of death, which contributes to a perception of a natural death. Henwood's (1999) Principles of a Good Death includes a similar factor, namely the fact that life should not have been unnecessarily extended.

4.5.4 Pain control

There were no non-responders to the statement, therefore HD $n_1=34$ and CD $n_2=24$.

Chart Twenty – Pain control



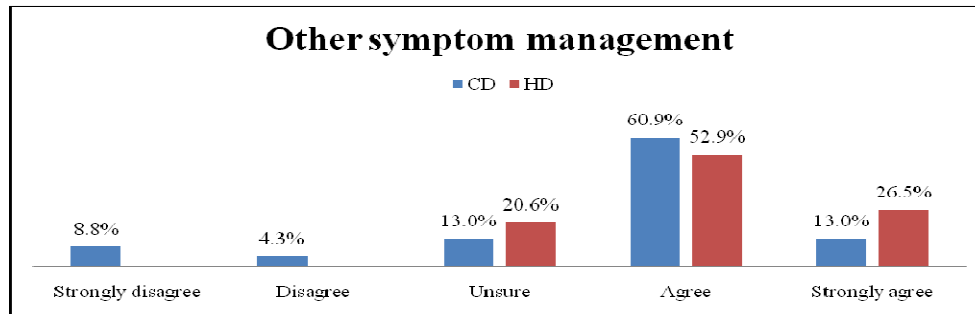
Over 75% respondents in both categories reported that they felt pain control had been adequate, with the respondents who experienced a hospital death recording a higher level of agreement than those who experienced home deaths. A higher number of HD (23.6%) respondents than CD (8.4%) did not believe pain control to have been adequate, suggesting that effective pain control is easier to achieve for in-patients than in a home care situation. This observation has been noted elsewhere (Wheatley and Baker, 2007) and may relate to ease of availability of medications, and the presence of confident staff to administer analgesia as prescribed.

This statement is the first of two referring to physical comfort for the dying person, and was included because the fear of pain and the witnessing of pain in another person are known to be both disturbing and anxiety provoking experiences in terminal cancer care (Given et al, 2001; Phillips and Reed, 2009). Freedom from pain is regularly listed as being an important component of Good Death (Emanuel and Emanuel, 1998; Henwood, 1999; Steinhauser et al, 2000; Kehl, 2006).

4.5.5 Management of other symptoms

There was a single non-response to this statement from the CD category, so totals are HD $n_1=34$ and CD $n_2=23$.

Chart Twenty One – Other symptom management



During terminal illness, there may be several physical symptoms such as nausea, confusion, or shortness of breath that can be relieved in various ways, including the appropriate use of medication (Higginson and Costantini, 2008; Kehl, 2008). This statement was included to elicit a further response regarding the physical comfort of the dying person as perceived by the respondent recognising that having symptoms well managed is another factor in the list of contributory factors to a Good Death (Henwood, 1999; Kehl, 2006).

The study found that the respondents in the HD category felt more assured that physical symptoms had been controlled than did the respondents from the CD category. A total of 13.1% of CD respondents did not feel symptoms were well managed, which is regrettable in a hospital environment, but may also reflect on the reason for hospital admission at the end-of-life.

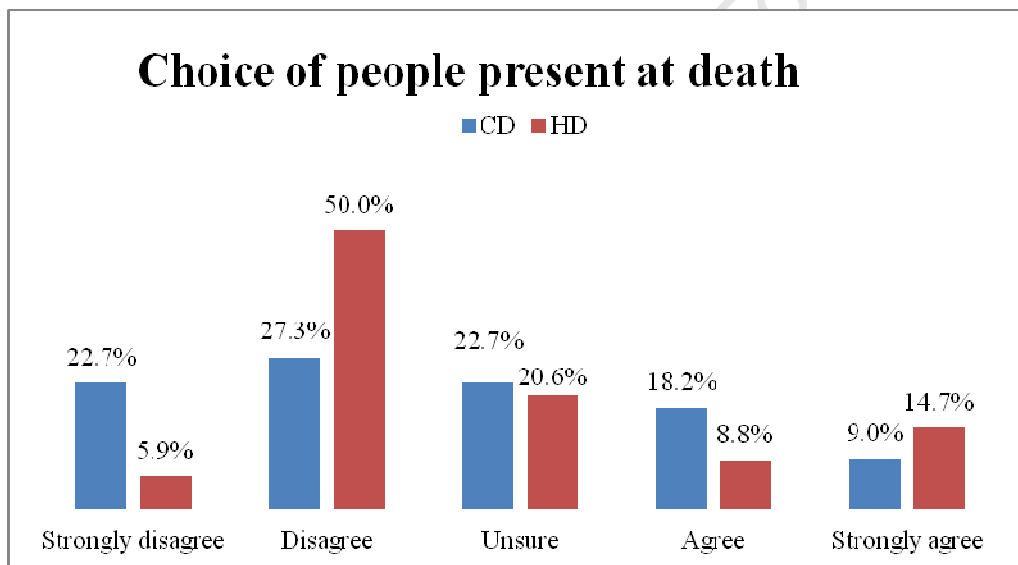
Anecdotally, the researcher can further report that often family members of a dying patient may not understand why certain signs or symptoms occur during the dying process, and may further not appreciate some of the medical rationale behind symptom control in a ward situation. This highlights the need for education and information, even in the terminal phase of the patient's illness, and this role of supportive informant can be well played by the social worker who may be able to interpret physical changes for the family, and reassure them in terms of achieving comfort for the patient. Again, the importance of communication between health care team and the family is emphasised in order to help all parties anticipate the death and to prevent prolonged or complicated grief (Grande and Ewing, 2009).

In an overall sense, well managed symptom control is seen as a contributory factor towards enabling home death by several authors, with the corollary that patients whose physical symptoms are not well controlled tend to require admission for care, and hence may not die in their home environment (Brazil et al, 2005; Bell et al, 2010).

4.5.6 Choice of people present at death

Two respondents from the CD category did not respond to this statement, making totals HD $n_1=34$ and CD $n_2=22$

Chart Twenty Two – Choice of people present at death



The responses to this statement indicated that for at least half of the respondents, there had not been discussion about who should be present at the time of death HD 55.9% and CD 50%. The possibility of having a choice about who may share the intimate journey of witnessing the patient's death may not have occurred to respondents, hence the lack of advance discussion about this. It is also possible that this sort of discussion was too emotionally painful to embark on for the patient, the family or both. Although this topic had may not been discussed with many of the respondents, the Western concept of a Good Death frequently suggests that the dying person have company (if so desired) at time of death (Henwood, 1999; Steinhauser et al, 2000; Kehl,

2006). From the researcher's professional experience, there is often a concern on the part of the dying person carers not to die alone and the carers may have a need to be present at the end of life.

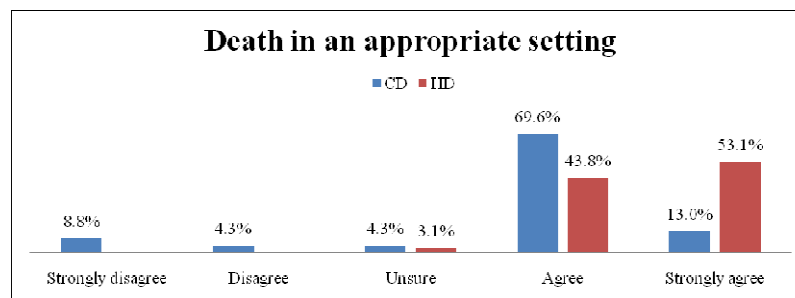
A part of the concern about dying alone may relate to cultural beliefs and required religious practices (Woof et al, 1998), or social pressures to have others present when a person dies. There may also be anxiety on the part of the dying person about the final moments, with a desire for company and the presence of others at that time. Likewise, carers and family members may also have a fear that the dying person may experience additional or unusual symptoms during death, which they could possibly prevent or alleviate by being present.

The possibility of expressing a preference about who should be with one during dying is an affirmation of the individual's autonomy and right to choose, and the issue of patient self-determination is growing in importance in the realm of Palliative Care (Borreani and Miccinesi, 2008). A study of attributes important at the end of life to groups of patients, family members, physicians and other health care providers found that the presence of family at time of death, ranked as the third most important factor to patients and family members, on a list of nine attributes (Steinhauser et al, 2000).

4.5.7 Death in an appropriate setting

A total of three respondents did not mark a response to this statement, giving totals of HD $n_1=32$ and CD $n_2=23$.

Chart Twenty Three – Death in an appropriate setting



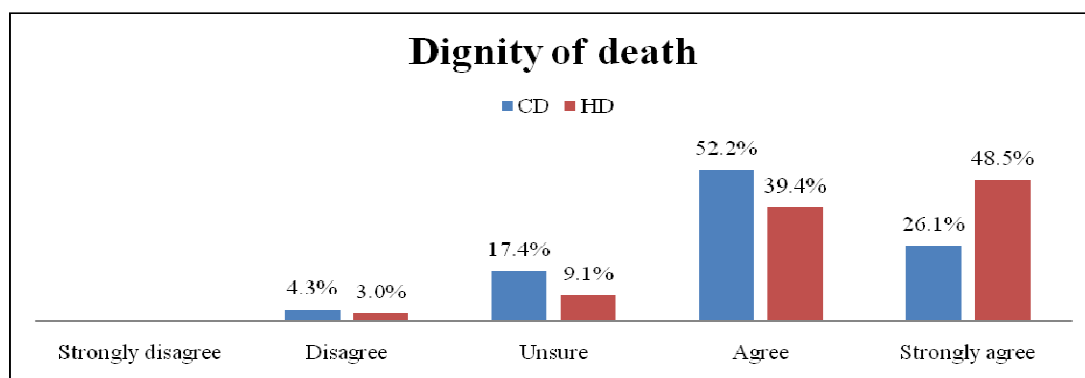
Statement 25 requires respondents to comment on the appropriateness of place of death in their own opinion, rather than to reflect on what the dying person had or had not discussed in this regard. The statement is phrased to avoid judgement of the respondent, as there may be instances where preferred place of death and actual place of death do not align, for a variety of reasons (Thomas et al, 2004).

Nearly all of the respondents in the HD category agreed that death at home had been appropriate (96.9%), with the remainder of respondents being Unsure. Despite the often-held belief that death should occur at home (Steinhauser, 2000), 82.6% of the CD respondents agreed that death had occurred in an appropriate setting, with 13.1% disagreeing with this statement. The fact that the majority of CD respondents supported this statement suggests that they had some measure of acceptance of a death in hospital, perhaps recognising that care at home would not be possible or advisable, and perhaps including a sense of relief that the responsibility for care was being taken by professionals.

4.5.8 Dignity of death

Two respondents did not mark a response to this statement, giving totals of HD $n_1=33$ and CD $n_2 = 23$. None of the respondents strongly disagreed with the statement. More of the HD (87.9%) than the CD (78.3%) respondents agreed that the death had been dignified, but both figures represent a majority. Several of the CD respondents (17.4%) were Unsure in their response, and a small number in each category did not agree with the statement.

Chart Twenty Four – Dignity of death



The final statement of this section could be considered a summary of the respondent's perceptions of the dying process, and potentially embraces several of the previous statements – for example, aspects of a natural end to life, physical comfort of the dying person, appropriateness of timing and place of death, and the dying person's ability to have expressed preferences about their dying process.

The term dignity was not defined or explained in the questionnaire, therefore allowing respondents their own interpretation of the statement. Despite this lack of a clear definition, the concept of dignity in death is one that the lay-public tends to equate with peacefulness, privacy and the absence of highly technical medical equipment or machinery such as one encounters in Intensive Care Wards. Dignity remains a subjective concept but appears to be universally desirable in terms of dying, and is featured in many works on Good Death, as explored in the Literature Review.

4.6 Open ended questions

The following two questions requested responses in people's own words, allowing space and time for reflection towards the end of the questionnaire. There were no correct or incorrect responses.

4.6.1 General evaluation of experience

Not every respondent completed these questions, with one from the HD category leaving Question 27 blank. There was a variety of responses ranging from a single or simple words to more detailed accounts of the dying process the respondent witnessed, and expressions of the respondent's own emotional experiences. The list of responses is provided below in categories of HD and CD respondents, excluding inappropriate or nil responses, but retaining the full content of responses to convey some of the emotion behind the written words.

Table Nine - Verbatim account of how respondents in HD group experienced the patient's death

H1	I was present during the final days and even though one can never be prepared to be present when one's parent dies I felt as a family we were able to provide her with a dignified death.
H2	Sad. Yet happy suffering was over.
H3	We'd been married for 54 years - I was destroyed.
H4	I was hurt as a normal feel appeared seeing that he was my husband, friend and companion, but I was satisfied that he was not suffering any more.
H6	With enormous frustration and anxiety.
H7	Traumatic (as in the noise), happened very fast, in the beginning but thereafter it was very quiet.
H8	As his eldest daughter, it was very traumatised, (be) cause we are a very closed family although we planned a spiritual preparation on that specific day. I had to be strong on behalf of everybody.
H9	Shock but glad no more pain for him.
H10	I have lost my dearly beloved husband and soul mate. We have truly been blessed with a wonderful marriage. Where he is now, there is no more suffering and pain.
H11	As traumatic as it was to lose my husband of 45 years, I was relieved that his pain was over.
H12	Rather shocked. The last couple of days moved from fairly well to weakness. Only after her poor last night it became clear that she was actually dying.
H13	Sad but with relief that my husband's pain was over and the he was now with the Lord he loved.
H14	Like wanting to go with her. I had no wish or purpose to live.
H15	Very peaceful and in control with good support.
H16	My wife was very talkative at the early part of the evening. She also said she was going to die that night (which happened). She also said that we must remember all the good things. I was tired and suggested we rest a bit. At 00h00 I work up and at 01h00 she died. I was confused at that very moment.
H17	The months and weeks leading up to the death were traumatic, but the death itself was almost a relief, as my mother was suffering - she had insisted that she did not want morphine, so we kept the doses low.
H18	It gave me a lot of self control of my life. Knowing that I was there with him at the last, even seeing him dying.
H19	Rather stunned as I did not expect him to go so soon, but thankful he did not live on to suffer.
H20	Being well prepared and knowing she no longer had a quality of life I felt relieved once

	she died.
H21	Overwhelming sense of relief that my life's partner was no longer suffering.
H22	Was traumatized at first but accepted later.
H23	At first shock later gratitude because it was peaceful.
H24	Peaceful until the last few hours, where I thought my husband was in pain and should have been given more morphine.
H25	I was shocked that it came so soon.
H26	I personally felt a lot of sadness - my Dad was one of my closest family members, though he was most of the time away from us as a family. I was glad I could spend the last weeks of his life with him.
H27	Very sad and a huge sense of loss, left a hole inside me.
H28	As a release for the deceased a relief and a terrible loss for the surviving family a dreadful loss, but a time to let for the sake of all.
H29	Peaceful and calm.
H30	Peaceful and quiet.
H31	With the help and support of Dr CB it was as good as could be expected.
H32	Sooner than expected. Death is so final. Wish he had had less pain. Confusion (mine).
H33	Painful.
H34	14 hours prior Dad's breathing changed and we knew he was at his last night. Brother, closest lady friend and I spent the whole night with him, talking quietly, reading Bible, soft music and pets with us. As soon as we all 3 stepped out of the room, he slipped away.

Several of the Home Death respondents provided quite detailed accounts of their experiences and captured both the physical observations and their own emotional reactions to the death. These were found to be more in-depth in terms of content than the responses from the CD group, which generally used fewer words to describe their experience. Although there were some expressions of relief from this group, the researcher suggests that many of the CD respondents preferred not to dwell on their experience with death too much, and hence chose short responses rather than providing lengthier narratives. Responses from people in the CD category were often more negative in tone, referring to personal anguish or disappointment and anger regarding care received, which may explain the more cursory response to this question.

Table Ten - Verbatim account of how respondents in CD group experienced the patient's death

C1	Terrible loss.
C2	Calmly, peaceful.
C3	Very disappointed with the availability & openness of doctors. I decided doctors were terrified of being frank and didn't like seeing us.
C4	Happy that I was with him. Relief it was over, coming to terms with being alone.
C5	Traumatic!!
C6	Very difficult, felt that he was cheated out of life, too young to die and we were very close to one another.
C7	Expected.
C8	Painful.
C9	Sense of relief for him and sadness for ourselves. We knew him to be in a better place as we are Christians.
C10	Sad but dignified.
C11	Feel abandoned.
C12	I was satisfied because I knew he was in pain all the time.
C13	I was not expecting it so soon. Had not been prepared.
C14	Like losing the most precious part of your heart, soul, of you.
C15	It was very peaceful and I was holding his hand.
C16	Very traumatic, a lot of pain at the end and minimal consciousness of my mum, staff pretty nonchalant!
C17	I felt completely helpless. The nursing sisters on duty at the ward were slow to respond and didn't appear to know what to do or very sympathetic. (Most of the other sisters however had been great on our numerous other visits.) We were unfortunate though to get the "useless ones". We felt frustrated.
C18	With grief, however I've accepted it.
C19	Traumatic.
C20	Traumatic.
C21	Was not present at the time - saw him 7 hours previously - felt at peace when arrived & spent 2 hours with him after he died. Wonderful time to reflect.
C22	Losing my wife was still a shock even though I knew she was dying, it all seemed quite sudden & too real in the end.
C23	Traumatic - I was a complete wreck for nine months after my husband died.
C24	It was and still is a very difficult experience, especially if you've seen them suffering in pain.

Responses to this open question varied from comments expressing sadness, shock or concern to expressions of relief and gratitude. To allow for easier review of the responses, the themes identified have been categorised as follows:

- Preparation for the death itself and the role of the family
- Descriptions of emotions
- Spiritual observances
- Commentary on the physical process.

4.6.1.1 Preparation for the death itself and the role of the family

These responses reflected a mixture of people who did not feel ready for the death, or that it happened too suddenly, and those who felt prepared, supported and that circumstances leading to the death were under control. The researcher has observed that it is not always possible to give family members good preparation for death. Death from advanced cancer can occasionally occur suddenly but usually features a progressive deterioration to unconsciousness and demise (Woof et al, 1998). Many physical factors may contribute to the actual dying process, and this can be difficult for patients and family members to understand at times, when their need is for facts and certainty. If the caregivers or family members do not feel that they are receiving accurate communications from the medical team, they may in turn feel better prepared for the death when it arrives (Steinhauser et al, 2000; Friedrichsen, 2003). Some people may wish to have details of that they expect if they are unfamiliar with the dying process, and will find conversations with professionals helpful, or printed material may be useful to consult as a reference.

An example of such information is the South African publication, “Dying: A practical guide for the journey” (Wood and Fox, 2005). At the same time, the family members may be conflicted within themselves – wanting to have certainty about when and how the death will happen, not wanting the patient to physically leave them, wishing for an end to perceived suffering, and wishing to control how the process proceeds. The waiting for death is a difficult and often-variable time for observers. For those with an emotional attachment to the dying person, it can be agonising. Sudden or unexpected death even when the patient has advanced cancer can be a shock for family members.

Comment was also made in response to this question about a sense of duty to be emotionally strong for other family members, and to assist the dying person towards a dignified death. This may allude to the respondent's own needs to be seen as possessing inner strength and self control which can be enhanced when there has been an opportunity for Anticipatory Grief (Chochinov et al, 1999; Grassi, 2007).

It is reported by Grassi (2007) that caregivers and family members who are prepared with information and support from health care teams for the death of a loved-one due to cancer reported that this service had assisted them in dealing with their own bereavement process. The benefit of information regarding the patient's condition and imminent demise is reported to help caregivers to be mentally prepared, organise their day-to-day activities, and to provide information to others within the family and social circle (Friedrichsen, 2003). These factors link to the perception of respondents that they had a central role in terms of supporting family members, whilst feeling the obligation to help the dying process achieve a dignified end.

4.6.1.2 Descriptions of emotions

Many words were used to describe feelings of loss and grief, and this grouping of emotions was the mostly commonly used theme by respondents in answering the question. Additionally, there were expressions of shock, and the word "trauma" or "traumatic" appeared in many responses, particularly those from the CD group. Respondents described their sense of confusion, helplessness or anxiety, with some commenting on feeling cheated or abandoned. Five people expressed relief in response to the question.

4.6.1.3 Spiritual observances

Three respondents commented that their faith had been helpful to them in coping with the death. In terms of being ready for the death of a loved one, it is not unusual for people to turn to their faith in search of comfort, support and spiritual guidance, as has been described by Pearce et al (2006).

4.6.1.4 Commentary on the physical process

Disappointment or frustration with medical staff was specifically noted by three respondents who had experienced CD. Three people from each of the HD and CD categories remarked that they believed pain control to have been insufficient prior to death.

A total of eleven respondents made comment on a peaceful, calm death, with four additional comments about the pain of the deceased being over with death. One person remarked on dignity observed in the death, and three other respondents expressed gratitude, or satisfaction with the dying process they had witnessed.

4.6.2 Description of a good death

Two respondents from the HD and one from the CD category left Question 28 blank and these are therefore not included in the tables below. As in the previous section, the full written responses have been included in the tables below to add richness and texture to the summary of themes that is presented after the tables.

Table Eleven - Verbatim account of how respondents in HD group described a Good Death

H1	No. We struggled with pain management right until death.
H2	No pain. Family around.
H3	Unexpected and instantaneous.
H5	Pain free as well as assisted meditation to relieve any anxiety.
H6	A person who acknowledges their condition and together the best is going to be done to help that person in their own death.
H7	Having said goodbye to all loved ones accepting your illness, going on to a better place peacefully, to die with dignity.
H8	As New Apostolic Faith, we know how to be prepared and what is expected. Prayer, read out of the Bible, and choral music - he died peacefully after such preparation.
H9	Only if alternative is worse.
H10	Peace in the heart and mind. He is now with the Lord. We spoke about it and he said "I am not afraid to die".
H11	Pain free, surrounded by loved ones.
H12	Sure of "eternal salvation" and the future. Not in great pain - no real regrets.
H13	One where death holds no fear or terror for the person. My husband was a devout Christian and, like myself, knew where he would spend eternity so death was not the end.
H14	An instantaneous death.

H15	Carrying out the wishes of person concerned, contentment in a peaceful setting with spiritual support th
H16	To die in your sleep.
H17	Peaceful, free of pain, with loved ones present.
H18	By not suffering for a long period.
H19	If the person fades away without suffering.
H20	1) Where one chooses to die 2) some family present 3) pain free (if possible) 4) with relatives fully aware of imminent death 5) with dignity.
H21	A death through natural causes where pain is controlled and that person still has dignity.
H22	Peaceful and dignified.
H23	Pain free and dignified.
H24	Peaceful, relaxed not agitated.
H25	Not to have prolonged pain.
H26	He was ready to go and I could feel in my heart he was content. Had the time to say how much he loved me, and he was ready to go.
H27	Having a chance to say goodbye.
H28	Surrounded by all who love you - knowing that this is the case and ready to let go, unfortunately my children were unable to be there but were able to speak via telephone and love was expressed and understood all round.
H30	No pain.
H31	Dying at home with perhaps the assistance of a nurse on call and NO LIFE SUPPORT (euthanasia would be preferable).
H32	Quick as possible and painless as possible. Apart from his cancer my husband had a stroke 7 years before and could not talk or walk.
H33	With the Lord.
H34	In a person's home, with loved ones around and beloved pets. Peaceful, spiritually prepared, lovingly treated with sensitivity for all needs.

Similarly to the previous open question, it is apparent that the HD respondents were more expressive than the CD respondents, who generally selected fewer words, and used shorter phrases or sentences to describe their version of a Good Death. It is difficult to know how to interpret this tendency, apart from the suggestion that there may be some avoidance of the topic, which may have been too provocative to focus on at length. At this point, it may be helpful to recall that most of the CD respondents had experienced their bereavement less than two years before completing the questionnaire, so possibly felt more emotionally vulnerable than the HD respondents, the majority of whom experienced their loss more than two years prior to the study.

Table Twelve - Verbatim account of how respondents in CD group described a Good Death

C1	Is there such a thing.
C2	Peaceful.
C3	Know in advance, surrounded by loved ones, painless. Important to say goodbye.
C4	One which my family would not have to suffer having to look after me, and die with dignity.
C6	Peaceful, without pain and not prolonged.
C7	A good death was received.
C8	As comfortable and painless as possible.
C9	One in which the dying person was ready to move on.
C10	Relieved of pain and with dignity.
C11	When the person keeps their dignity.
C12	Maybe if you die instantly. So no death is a good death.
C13	In a comfortable, home environment with family - just slip away.
C14	Dying peaceful.
C15	As above (It was very peaceful and I was holding his hand).
C16	Person is at peace, and has been able to say goodbye to necessary parties, is happy with where they are.
C17	One without pain or fear or least only a little fear. One where you felt that everything possible had been done. One where the victim and family had had a chance to say everything they needed to say. One where the dying person was comfortable.
C18	Going peacefully.
C19	Dying quietly while sleeping.
C20	If a person is terminally ill and there is no hope, why should said person die a painful death?
C21	Not opening their eyes - just "drifting away" painlessly!
C22	There is no dignity in death. But having friends and family around and being comfortable is good!
C23	Getting into bed at night and not waking up in the morning.
C24	Leaving peacefully.

As with the previous question, responses were expected to be subjective, yet could still be categorised into broad themes following similar topics to those noted in the previous section:

- Preparation for death and the role of the family
- Quality of care and Place of Death
- Spiritual observances

- Preferred physical processes.

4.6.2.1 Preparation for death and the role of the family

This category had nine respondents comment on the importance of loved ones being present at the time of death, and additional responses regarding readiness for death. There was a preference for “no regrets” in dying, and a need for acceptance by the family and dying person of the inevitability of death which would enable leave taking and completion of relationships.

As discussed in Chapter Two and earlier in this chapter, there is evidence that people who have had the opportunity for emotional preparation prior to the death of a loved one, cope better with the grieving process (Worden, 2003; Grassi, 2007). In terms of components of a Good Death, Henwood (1999) includes readiness for death and the opportunity for both the dying person and the loved ones to say goodbye as being contributory factors, as is indicated by respondents to this question.

From the perspective of the dying person, Henwood (1999) and Kehl (2003) both list that having a choice about who is present at the time of death assists towards a Good Death, with this aspect identified by the respondents to this question as being of significance. The presence of family or loved ones was specifically mentioned by several respondents, with one person suggesting that dying without being a burden to others contributes towards Good Death.

4.6.2.2 Quality of care and place of death

The assistance of compassionate and competent carers, and the knowledge that everything possible had been done to assure the comfort of the patient were additional responses referring to quality of care for the dying person. Linked to the quality of care received and the nature of the overall dying process, four HD and three CD respondents specifically stated they believed that dignity was essential in a Good Death, a factor which was identified by Henwood (1999) and Kehl (2006) in their lists of contributors to a Good Death.

The element of choice in the place of death, with a preference from three respondents for death at home was also included in the written responses to this question. The fact that a relatively small number of the total respondents cited a home death as being important in order to achieve a Good Death, suggests that this is not a major concern, with aspects such as pain management or the presence of family taking precedence.

4.6.2.3 Spiritual observances

Respondents to this questionnaire represented different religious backgrounds, and eight people commented on the importance and helpfulness of religious preparation and certainty about the hereafter for the dying person. Steinhauser et al's (2000) summary of attributes at the end of life considered to be important by different groups of people involved in Palliative Care ranked nine key factors, of which being "At peace with God" was rated the second most important factor by patients and bereaved family members from a variety of religious backgrounds (Steinhauser et al; 2000: 2481). Woof et al (1998) emphasize the importance for the patient and the family of religion in the dying process, in terms of the comfort and certainty belief structures may bring, as well as the role that ritual and religious observances may play for people. Whilst deaths in hospital occur in a medical and professional environment, the care of the whole patient and family requires that religious and spiritual practices be respected during terminal illness (Woof et al, 1998).

4.6.2.4 Preferred physical processes

This category of responses drew the largest number of comments. Seventeen people specified that a Good Death should be pain free, with two stating there should be "no suffering" although this phrase was not defined. The importance of pain control as a major contributor to a Good Death is highlighted in literature based on studies in various countries (Steinhauser et al, 2000; Miyashita et al, 2007; Leung et al, 2009). In an American study of different groups of people involved in end-of-life care, Steinhauser et al (2000) found that patients, bereaved family members, doctors and other carers all ranked the control of pain as being the most important of nine suggested components of a Good Death.

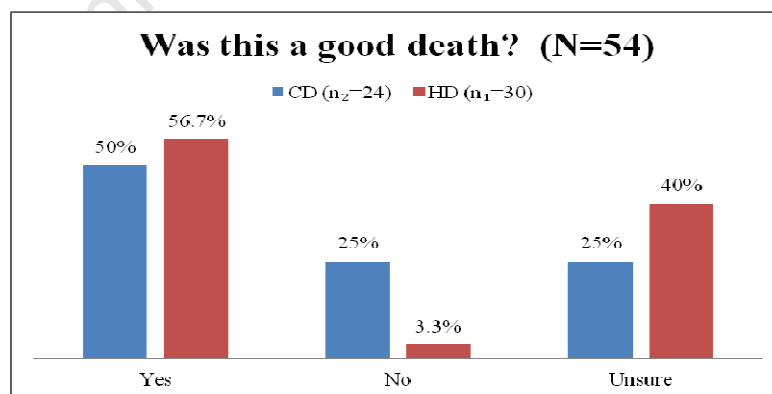
There were additional comments on a Good Death being from natural causes, quick or at best not prolonged, or death while asleep as being desirable. Four respondents required that anxieties and fears be managed, including the use of medication for this if necessary. The researcher has wondered if this concern reflects the respondents' own anxiety or fear witnessing the dying process and possibly feeling the need for reassurance that Wood and Fox (2005) describe as being essential for patient and carers in the terminal phase of illness.

Eleven people stated that a peaceful death would imply a Good Death, although again the use of the term was not elaborated on by respondents. It is speculated that "peaceful" could refer to physical comfort and a lack of outwardly observable signs of physical distress (for example agitation or difficult breathing). However, the term could also refer to the care environment, or could refer to spiritual readiness as discussed in the previous section.

4.7 Was this a Good Death?

Four respondents from the HD category did not indicate a response to this question, giving a HD $n_1=30$, with CD $n_2=24$, and a total $N=54$.

Chart Twenty Five – Was this a Good Death?



This final question on the questionnaire provides an answer to the research objective of assessing whether the family members thought the death they experienced was Good Death. Respondents were asked to reply with a Yes, No or Not Sure. As not all respondents answered this question, percentages of the total responses are used to make for easier comparisons.

Half of the CD respondents replied in the affirmative to this question, and 56.7% of the HD respondents also believed this to have been a Good Death. A quarter of the CD respondents were not sure, and a quarter replied that they did not believe that it was a Good Death. While the HD respondents had higher numbers of Not Sure responses(49%), they had a lower number of No responses, with only 3.3% of those observing a Home Death who did not believe it to have been a Good Death.

In reviewing the responses to this final question there are two main findings that are apparent:

- Good Death is possible in an acute care hospital ward

Despite the perception that hospitals are not ideally suited to providing quality Palliative Care to people dying of cancer, half of the respondents to this question from the CD category felt that the death was in fact a Good Death.

- Not all deaths at home are Good Deaths

Challenging another commonly held perception, or expectation that death at home should necessarily be Good, there was a small percentage of respondents (3.3%) who replied that the Home Death was not a Good Death, with a further 40% of respondents from that category Unsure. The extension of this observation is that not all Home Deaths are Good Deaths.

In essence the responses have indicated that Place of Death alone does not determine whether it is a Good Death or not. This concurs with the finding of Steinhäuser et al (2000) that dying at home was not ranked as the most important component of a Good Death by a variety of role

players. What does emerge from the literature is the aspect of patient and family choice and control over Place of Death, and how this is seen as upholding the Palliative Care principle of having the patient and caregivers involved in decision-making processes while reflecting the rights of autonomy, self-determination.

4.8 Conclusion

The questionnaire, with its separate sections of information and opinion gathered from a total of 58 respondents, has been analysed in parts and as a whole. Certain respondents added comments at points in the questionnaire, and used additional space provided to share their thoughts.

The analysis of the data has provided some clear observations that will be used to address the Research Objectives in the following chapter. Over and above the data gathered and reported on, there appear to be possible relationships between factors that may contribute towards Place of Death for patients – for example the age and gender of the patient (it appears younger women die more in hospital and older men die more at home), as well as the potential association between factors such as having a paid carer/helper in place at home and home deaths. These relationships could be explored by further statistical analysis, but this information is not specifically required to respond to the Research Objectives, so would be a venture beyond the current study.

The final chapter follows contains Conclusions and Recommendations from this work, and will highlight the salient points that require closer examination, or future exploration.

CHAPTER FIVE

Conclusions and Recommendations

5.1 Introduction

The final chapter begins with conclusions based on the demographic information gathered, followed by conclusions relating to the four identified Research Objectives that were specified in Chapter One. The chapter then presents recommendations based on the conclusions and a commentary on possible avenues for future research completes the chapter.

5.2 Basic demographic information

5.2.1 Relationship of the respondent to the deceased

The respondents were able to provide accurate and insightful responses to the questionnaire. Most of the respondents were spouses or life partners of the deceased which placed them in a position to respond appropriately to the questions about the patient's dying, drawing on intimate relationships and on extensive contact with the patient during the end of life phase.

5.2.2 Age and gender of the deceased

Cancer is a disease of the elderly, with the average age at death in this study being 67.12 years. The higher proportion of male deaths compared with female deaths in the study reflects the global tendency for more men than women to die of cancer. The male patients were on average older at death than female patients, with men dying at home being the oldest sub-group when place of death and gender were compared. This observation indicates that older men had adequate support on a day-to-day basis, whether from younger spouses, extended family or paid caregivers. The sub-group with the youngest median age was that of women dying in hospital, which suggests that domestic circumstances were not able to support terminal care for this group at home. The conclusion regarding social support for care at home links with international studies reflected on previously in this study.

5.2.3 Primary site of the deceased's cancer

Lung cancer was the highest claimant on patient lives in this study. This is consistent with global statistics, with the next largest categories primary cancer sites namely colo-rectal, prostate and breast cancer all confirming that the population being studied fits the Western profile of cancer mortality.

5.2.4 Place of death

Most of the respondents experienced death of the patient at home. Dying at home requires support and practical assistance when there is a progressive decline in the patient's condition. The role that family members and caregivers are responsible for in assisting the dying patient towards a death at home cannot be underestimated.

5.2.5 Time elapsed since death

Respondents to this study indicated varying lengths of time since the death of the patient, with no one category of time interval clearly standing apart from another. There were respondents whose experience of loss was more than three years previous, and their participation in the study suggests that they felt they had a specific contribution to make with their responses. The clarity with which people recalled their experiences illustrates the profound nature of human grief and the impact loss can have on a person's memory.

5.2.6 Respondent's role as Informal Carer

Most of the caregivers in the study were spouses or life partners, which required them to be intimately involved in patient care, running the home and possibly continuing to work outside of the home. The role of Informal Caregivers is complex and demanding, and it has been noted elsewhere in this report that Informal Caregivers are at risk for burnout requiring considerable additional support during their tenure as carers.

5.2.7 Employment of additional help

Patients who died at home made more use of paid assistance than those who died in hospital. This finding surprised the researcher who had not realised in the course of clinical work that a large percentage of households who managed care at home until death used additional paid help to care for the dying patient.

5.2.8 People present at the moment of death

The majority of patients died in the presence of another person, with a variety of people being in attendance at time of death. Those who were not sure if the patient died alone or not came from the CD category, suggesting that the hospital had not offered that specific information to the family, or perhaps the family members had not enquired.

As the duration of the dying process varies, and death may be sudden, it is often difficult for family or friends to be summonsed and present at the correct moment to support the dying person. The issue of company during dying or witnesses to a death remains an individual choice that may be steeped in culture and ritual, in which case it would be understood by family and friends within that social context and hence may not be fully appreciated by outsiders or staff involved in the patient's care.

The researcher suggests that in cultures where death is not traditionally discussed or anticipated, there may not be preparatory arrangements for company during dying. Although not true in all instances, this uncertainty or lack of clarity about procedures and physical presence could potentially leave space for doubt or uncertainty about the nature of the death in the mind of the survivors. It may be difficult for surviving family or friends to establish whether the deceased was asleep or awake, comfortable or otherwise, conversant or not at the time of death. These details would then be absent from any account a family member wanted to share of the deceased's dying moments, and might impact on their ability to emotionally deal with the loss, and to proceed with the grieving process.

5.3 Conclusions based on research objectives

5.3.1 Objective One: To establish the place of death of patients from a private oncology unit during the period 01 January 2008 to 31 October 2010

It was established that the majority of patients from this unit who died cancer did so in their home environment. Of the two categories of respondents to the postal questionnaire, the majority were people who had experienced a death at home. Literature indicates, and clinical experience suggests that most people would prefer to die at home.

5.3.2 Objective Two: To record the family members experience the patient's death

Several words, phrases and themes recurred in the description by respondents of the patient's death. The words chosen reflected the individual's grief reactions with familiar or colloquial words being selected by respondents. The researcher's instruction was to respond without too much pre-meditation, so word selection of respondents is respected and accepted as it was provided.

Ten people used the word "trauma" or "traumatic" to describe their experience which holds connotations of a deep and possibly harmful emotional experience. More than 80% of respondents indicated in response to an earlier statement that they understood that the person was dying suggesting that despite some preparation for the death there was still a sense of distress associated with witnessing the dying process.

Inadequate pain control was a concern for some of the respondents. This aspect of end of life care is one of the primary goals of end-of-life care and is a concern for medical professionals working with the dying.

Anger was noted towards some of the medical staff, including doctors and ward staff. While it is not possible to contextualise the individual expressions of anger, and the researcher suggests that these comments (some of which were quite lengthy) may have provided an opportunity for catharsis for the respondent. It is also possible that respondents hoped their feedback would lead to an improvement in care for future dying patients. Disappointment, bewilderment, anger and

confusion are common emotional responses to the loss of a loved-one, and may continue to be expressed in various forms during bereavement.

In contrast, there were several responses that reflected satisfaction and peace with the death experienced. The theme of a peaceful or calm death was mentioned by a total of 11 respondents, with five people commenting on a sense of relief at the death. These responses suggest that some people were prepared for and accepting of the patient's death.

It is not unexpected that responses to this open ended question were mixed and varied. There were 'positive' and 'negative' comments were made by all respondents, suggesting that observing and being part of someone else's dying remains an individual and unique experience whatever the place of death.

5.3.3 Objective Three: To list components family members believe contribute to a Good Death

Responses to the second open ended question about what factors or components respondents believed contribute to a Good Death were categorised into broad themes. As much of this study focused on the concept of a Good Death, the ten most cited words or themes are listed below, with the first three in descending order of frequency.

Top three components of a Good Death:

1. No pain, or pain free death
2. Peaceful death
3. To have loved ones, family and pets present at time of death.

Additional components of a Good Death:

- Dignity in dying
- To have spiritual and/or religious preparation and certainty about the hereafter
- Acknowledgement by or awareness of the dying person of their impending death
- Care to be loving, sensitive and competent
- Any anxiety or fears of the dying person to be managed (or medicated if required)

- To experience a quick, unexpected or instantaneous death
- Death at home.

The responses may have given voice to wishes for how the death “might” or “should” have been in the respondent’s idealised world. It is probable and desirable for the study that the responses provided were highly subjective and personal to the situation under discussion.

The list above is missing words such as “choice” or “control”, which is in contrast with lists compiled by other authors. This may indicate that the sample of respondents is not as aware of patient rights as those compiling lists from other more developed countries where there is a greater awareness of consumer rights or patient advocacy issues.

Death at home was cited by only three respondents as being a contributor to a Good Death, which suggests that although the idea of dying in one’s own home is important, it is not considered to be an essential component of a Good Death, with other issues taking priority. Furthermore, it can be speculated that having direct experience of the dying process, respondents were more realistically aware of the potential burden death at home can place on family members, so may have selected other priorities for defining a Good Death.

5.3.4 Objective Four: To assess how many family members think the death they experienced was a Good Death

The general response to this question was in the affirmative, indicating that a Good Death can be achieved at home, or in an acute care hospital. A quarter of the CD group did not believe the death in hospital was a good one, contrasted with one respondent from the HD group. Given earlier comments in this chapter about the death being perceived as “traumatic”, and knowing that several respondents expressed anger at medical staff, the researcher feels this may account for the 25% No response from the CD category.

Of interest is the large number of people from both categories who were unsure about whether the death they experienced had been a Good Death or not. This may indicate uncertainty in terms of evaluating the death, or a difficulty with the concept of death being “good” or “not

good”. For people who are experiencing profound grief, it would also be uncomfortable to actually term their personal loss as being a Good Death – this concept may be more easily examined from a distance than from a personal perspective.

5.4 Summary of conclusions

This study set out to explore whether it was the process or the place that contributed to the description of a Good Death by respondents. The researcher believes that the question has been answered by the collated findings and conclusions discussed above. It is neither the place nor the process alone that contributes to a Good Death, but a combination of the two, together with a variety of additional factors and considerations. Good Death remains a subjective concept.

The presumption that a Good Death is not possible in an acute care hospital ward has been challenged. The hope, wish or fantasy that death at home is automatically good, has also been challenged. By reviewing aspects of physical care, support and preparedness for the death of a loved one, the researcher has indicated that the concept of a Good Death is indeed a multi-faceted one, and that Good Death cannot be limited to one attribute alone. Place of Death is not the sole contributor, but the process of dying is not the only contributor to a Good Death either. Situational, environmental and emotional factors play a part as well, as indicated in the list of components of a Good Death gathered from respondents.

5.5 Recommendations based on the research

This section presents recommendations based on and extending from the above conclusions, with suggestions for practical ways of implementing improvements in providing care for terminally ill cancer patients.

5.5.1 Place of Death discussions

In order to assist individual patients and their families with planning for terminal care, a more structured approach towards discussions around Place of Death would benefit all parties involved in patient care. The medical team should establish the practice of discussing and recording patient preferences in terms of place of care, and place of death well in advance, ensuring that family members or caregivers are aware of these preferences. In order to prevent possible

disappointments or confusion, there should be a conversation about options to be considered if first choice is not practicable. Such a conversation, and the recording of it, would provide a reference point for all involved and extends to the patient a sense of some autonomy and control over their dying process. Limitations and practical considerations should be kept in mind, so that unrealistic expectations or impossible promises are not inadvertently put in place.

5.5.2 Improvement of care for hospitalised patients

Recommendation: Ward staff education

A basic and easy-to-achieve first step towards improving end-of-life care for patients is to engage with ward staff at the Constantiaberg Medielinic, with the intention of informing them of the findings of this research. Such an intervention would require liaison with ward management, and commitment to education of ward staff would need to be obtained, in order to ensure learning and improved care for the patients and families.

Recommendation: Introduction of Integrated Care Pathway

Although the oncologists managing patients are highly trained and skilled, it may be helpful to the patient, family and ward nursing staff if there was a more conscious “diagnosing of dying” for ward patients who are approaching death, as was discussed in the Literature Review. This would enable all medical staff involved in that patient’s care to understand what is expected to happen, and how to assist the patient and family towards death, possibly implementing an Integrated Care Pathway to provide an outline for medical interventions and procedures while the patient is in a hospital ward. The researcher believes that nursing staff in particular would benefit from more clear instructions regarding care for the dying patient in hospital. Such direction from the oncology team would enable ward staff to tailor their caring routine more individually to the patient’s needs, and should eliminate unnecessary procedures from being carried out on the terminally ill patient.

The families of the dying patients should also be more accurately informed of the anticipated approaching death by the oncology team and nursing staff so that they could be better prepared for the death. Ultimately, if patient and family are informed and reassured about comfort and symptom management, the dying process should be well managed within a hospital ward,

allowing the family to participate or witness as they are comfortable, and acknowledging the rights and needs of the dying person. A well managed dying process should ensure better prospects for the emotional recovery of survivors and the healthy resolution of their grief after the death has occurred.

Recommendation: Specialised Palliative Care practitioners in Oncology settings

The introduction of more specialised and focussed palliative care for patients could be considered by the GVI Oncology practices, whereby certain staff in different professional departments become more committed to the complexity and benefits of palliative care, and could offer a consultancy or specialised service to patients, family members and professional colleagues. This would entail a departure from the traditionally “curative” focus of oncology medicine in South Africa, but would also extend improved care and symptom control to patients who may otherwise feel abandoned, unimportant or like failures when their cancer becomes incurable and medical management moves towards the palliation of symptoms.

5.5.3 Support for Informal Caregivers

Acknowledging the burden placed on family members as Informal Caregivers, and recognising that spouses or life partners in particular are frequently placed in the role of carer, it would be helpful to find additional ways to support this group of people and to ease the load they carry in terms of care, decision making and running a household.

Recommendation: Assistance for Informal Caregivers

Without adequate emotional and practical support it is known that Informal Caregivers may become prone to depression and may in addition face more difficult bereavement processes. The researcher therefore suggests that whilst the patient’s comfort and care must be paramount, it would be beneficial to the next of kin of dying patients to ensure support structures are in place and that the carers know how and where to access support. A further option would be to develop additional resources for this group of people, in the form of information pages or directories. In countries abroad where public transport is more easily accessible and patient numbers are greater, support groups for Informal Carers have been run successfully and can fill an important psycho-educational function. In this country, telephonic or web-based support could be explored

or developed to provide information and guidance for people who are not able to leave their homes to seek support.

Recommendation: Compilation of a Caregiver Package

It is suggested that a Caregiver Package could be compiled to include information sheets about physical signs, tips regarding home nursing, a list of local resources including home nursing, equipment, funeral parlours and undertakers, advice on what to do following death at home and so on. Such a pack could be individualized according to the geographical area and resources could become standard information for each oncology treatment unit to pass on to patients and families when entering Palliative Care stage.

Recommendation: Practical support for Informal Caregivers

Frank discussions with the social worker about anticipated care needs for the patient can enable family members to actively take steps towards mobilising resources. It is possible that some people are unaware of help that may be available, particularly that of the St Luke's Hospice community sisters who can assist people in their homes provided the patient is referred timeously.

As an indication of patient support and advocacy for the improved terminal care of patients, the researcher recommends that a discussion with GVI management take place to explore the possibility of motivating medical aids for better end of life nursing care provision. Not all medical aids currently will authorise for payment of home nursing for the terminally ill, and the procedure for securing funds from medical aids is often unclear and frequently arduous.

Recommendation: Improved access to bereavement counselling for Informal Caregivers

The challenges of bereavement can be compounded when family members have had prolonged periods of caring and supporting the dying person. As discussed in this study, Informal Caregivers are at significant risk of depression following the death, and it is recommended that a screening tool be used by the social worker to assess, ahead of bereavement, which family members may be more in need of bereavement counselling so that services can be appropriately planned and put in place.

5.5.4 Potential for patient and family advocacy

There is a huge need for improved awareness in the public as well as within the medical communities of the needs and rights of people who have advanced incurable cancer. The needs extend from access to care, to nutrition, compassionate medical attention, appropriate medication and other practical support. The rights of this group of people are similarly varied and are championed by groups such as the Hospice and Palliative Care Association of South Africa. However, there is much still to be achieved. The researcher supports the power of collective voices, especially in terms of calling for policy changes, and raising advocacy issues wherever possible.

It is recommended that Palliative Care professionals take the responsibility of speaking up for their patients, to educating their peers and sharing information that will help promote improved care. Individual professionals can mentor and teach colleagues they encounter as they provide palliative care. Researchers and workers in the field should share their knowledge, their work, and take up the challenge of publishing details of their experiences and studies so that on-going learning is possible, and achievements within this country, however minor, can be celebrated in a more global environment.

5.6 Suggestions for further research

No academic study can explore all potential avenues and discussions that emerge during the research process. This work has begun to explore several aspects of end-of-life care and the dying process of people with advanced cancer. It could serve as a departure point for many other studies, so suggestions for future research topics are listed according to similar headings used in the preceding Recommendations section.

5.6.1 Explore the topic from a qualitative perspective

This quantitative study has yielded statistical data, and provided an interesting bonus in terms of narrative content that respondents added to their questionnaires. As was mentioned previously, there appeared to be a need for expression and reflection by some respondents, suggesting that a qualitative study could be developed with the intention of gathering richer, more in-depth

responses. This qualitative data would have use as a measure of quality of existing services, and would highlight potential needs or shortcomings.

5.6.2 Place of Death discussions

In the face of economic stresses for individuals, State health care facilities and private medical aids, and in the light of changing family structures, it would be interesting to review “consumer opinion” on Place of Death in this country. Studies have been undertaken abroad and have been compared regionally and internationally, but there has not been a similar study in this country that examines preferred and actual place of death, or one that has sought to understand expectations and attitudes of health care consumers. This type of information would assist policy makers in terms of planning and developing services, ultimately with the goal of providing appropriate and valuable care within the community

5.6.3 Improved care for hospitalised patients

- a) To improve care for ward patients in acute care hospitals, it would be of value to obtain insight into the views and attitudes of staff working with the dying cancer patient. Their level of medical and socio-cultural understanding could be assessed alongside their emotional and spiritual coping or resources to cope with a challenging and demanding aspect to nursing care. Focus groups could be conducted with ward staff to explore their perceptions and establish their informational and emotional needs regarding care of the terminally ill cancer patient. Based on such group work, ward or hospital management could be approached to address these needs.
- b) Additional nation-wide research into the needs of terminally ill oncology patients could be undertaken through the GVI Oncology group of practices, making use of their Electronic Medical Records system to capture data and to present a more convincing case to medical aids for improved end-of-life benefit provision.
- c) Similarly, a study of the medical reasons for patient admission to a ward could be used to assess the efficacy of home-based shortcomings and to identify areas for improvement. This information could be simply gathered by recording why patients were admitted to the ward prior to death, how long they remained in the ward and what their care needs were whilst there. If the correct format for information gathering were put in place, these details

could be gathered daily, coded and presented to the oncology team and shared with other involved professionals such as the Hospice community sisters who may share responsibility for patient care.

5.6.4 Support for Informal Caregivers

- a) In order to better understand the role and burden on Informal Caregivers, a qualitative study that explored the pressures, needs, challenges, rewards of this group of people would assist in planning for service delivery, and would enable health care providers to better meet the needs of Informal Carers, ideally with the effect of preventing physical and psychiatric morbidity.
- b) It is suggested that additional research could be put in place to explore in more detail what information patients and families would like to have regarding care at home prior to death in order to compile a Caregiver Package as mentioned previously in this document. It may be necessary to conduct a needs analysis or to hold focus groups with people who have been Informal Carers to terminally ill cancer patients.

5.6.5 Awareness, rights and advocacy

From a Consumer Rights perspective, a broad-based study examining perceptions of patient autonomy, and issues of control or choice in the terminal phase of cancer illness would provide feedback to medical professionals and institutions, and would give sociologists insight into areas of awareness or ignorance. Community based groups and services would be able to use this information to lobby for improved funding, better public education, or for more sensitising of professionals during their training, in order to improve service delivery to patients and families.

5.7 Conclusion

This final chapter has extracted specific conclusions from the data gathered, and has used these as a basis for making recommendations for improved practices and for future actions which may contribute to improved care for the dying and for their families. A list of suggestions for future research completes the chapter.

The central conclusion is that a Good Death in an acute care hospital is possible and could be achieved more readily with better preparation of family members, improved training and support for ward staff, and clearer procedures for oncologists and medical teams to follow in providing end of life care. The place of death may have some significance but is not the primary factor in determining Good Death – many factors are involved, most of which are common to different cultures or environments.

This chapter has drawn together salient points that emerged from the study. A wide variety of people, including medical professionals, mental health professionals and community based organisations are involved in providing care during the terminal phase of cancer illness. The study as a whole indicates the importance of considering the needs of the not only the dying patient, but those of the family members and informal carers as well, and therefore suggests possible routes for improving end of life care for both the patient and family.

“How people die remains in the memory of those who live on”

Dame Cecily Saunders:

Nurse, Social Worker, Medical Doctor and
Founder of St Christopher’s Hospice, London
(Quoted by Wood and Fox, 2005:125)

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APPENDIX A

Letter of permission to undertake study



27 February 2010

Clare Manicom
Oncology Social Worker
Constantiaberg Unit
Constantiaberg Medi-Clinic
Plumstead

Dear Clare

Permission for Masters Studies within GVI Oncology

Title of Research:

“Dying of cancer – is it the process or the place that contributes to a good death?”

We hereby grant you permission to use the names and contact details of deceased patients of the Constantiaberg Unit for your research project. We are comfortable with your research methodology and will require a copy of your thesis on completion for our library.

We wish you well with your research and look forward to your results and recommendations in this regard.

Yours Sincerely

Linda Greeff
Manager Of Psychosocial Support Services
GVI Oncology

14 Mispel Rd, Bellville 7530 . P.O.Box 15811, Panorama 7506 . info@cancercare.co.za . www.cancercare.co.za

GVI Oncology – Reg Nr 2001/0011467/07

Directors: L. Gouws, GJ Hart, CR Jacobs, KI Maart, JR Malan, G Davids and H du Toit
With units in Panorama, Constantiaberg, Port Elizabeth, George, Somerset West, East London, Pinelands & Nelspruit

APPENDIX B

Covering letter and Pilot Study Questionnaire

August 2011, Rondebosch

Good day

I'm attaching a questionnaire that am sending to people who have experienced similar bereavements to your own. As part of the research, this Pilot Study is being conducted with a small group of people to obtain responses to the questionnaire. Your responses and any comments on aspects of the questionnaire may help to modify what is used as the data collection tool for the study.

If you are willing to complete the questions in the pages that follow, please will you additionally consider providing specific comments on:

- Wording on questions
- Sequencing of questions
- Possible redundant questions
- Questions that you may believe to be missing
- Any confusing questions

As mentioned in the preamble to the questionnaire attached, you are welcome to be in touch if you would like counselling or bereavement support, and participation in this study is entirely voluntary, with results being collated and reviewed as a whole, without any disclosure of identifying particulars.

You may use the stamped, self-addressed envelope to return this page and the questionnaire.

I would be grateful if you could return both before the 26th of August 2011.

With appreciation for your observations and time.

Clare Manicom
Oncology social worker
clare.manicom@cancercare.co.za
0861 99 99 14

July 2011, Rondebosch

Dear

I am undertaking a study in order to complete a thesis for my Masters Degree in Social Work at the University of Cape Town. You may have met me or worked with me at GVI Oncology, Constantiaberg, while your family member or friend was receiving care for their cancer. I am the social worker attached to this unit.

My study will examine where patients from this unit die and how their death was experienced by those identified as “next of kin”. Data collected will be summarized to form the basis of my thesis and will contribute to the publication of an academic article. More importantly, trends and themes will be shared with staff of GVI Oncology throughout the country, so that medical teams can develop a better insight into the experiences and potential needs of dying patients and those involved in their care. I will be making the information available to the management at Constantiaberg Medi-Clinic where some patients were cared for at the end of their lives.

I have drawn information from our medical records and your name was provided at time of first registration with the oncology practice. The study includes deaths from between six months to two years ago.

It is understandable that reflecting on the death of someone you cared about may evoke emotional responses for you, and you are welcome to provide your contact details with a view to obtaining bereavement counselling at no cost to yourself. Otherwise, I do not need your name but would appreciate some basic information being completed in addition to answering some questions below. If you would rather not complete this questionnaire, please be so good as to return it to me in the enclosed envelope, even if it blank or partially completed.

The questionnaire should take less than 15 minutes to complete, and can be returned in the envelope enclosed. It would be helpful if you could return this by the end of August 2011. My sincere thanks for your time and your reflections.

Please provide some basic details, by marking the appropriate box with an X:

1) Your relationship to the patient?

Partner/spouse Parent Child Other relative Friend

Other relationship – please specify:

2) The age of this person when they died?

20 – 35 35 – 50 50 – 65 65 – 80 80 +

3) Their gender?

Male Female

4) What type of cancer did they have when they first came to the oncology practice? (If you are not certain, then please indicate Not Sure)

Bladder

Breast

Brain

Colon or rectum

Gastric (stomach)

Lung

Melanoma

Ovary

Pancreas

Prostate

Not sure

Other – please specify:

5) Where did they die?

At home

At Constantiaberg Medi-Clinic

In another place (specify)

6) The date of their death?

7) Would you describe yourself as being the main carer for the person who died?

Yes

No

Not sure

8) Did the patient have any visits from the local Hospice staff members before death?

Yes

No

Not sure

9) Was anyone employed to help care for the deceased in the home environment?

Yes

No

Not sure

10) Was anyone present at time of death?

Yes

No

Not sure

11) If you answered Yes to the question above, who was present at the time of death?

Spouse or life partner

Parent

Child

Sibling

Other relative

Member of medical staff or Hospice team

Minister of religion

Friend

The following statements focus on the last week of the dying person's life. Please record your *immediate* responses to the statements based on your experiences and observations, by marking an X on the line under the word that matches your opinion most closely. There is no wrong or right answer, *please respond as you understood the situation to be*. If you are uncertain, indicate that this by responding Unsure. There is space provided at the end of the questionnaire for additional comments.

1) The dying person understood that they were dying

Strongly disagree Disagree Unsure Agree Strongly agree

2) The dying person had some control over their care before their death

Strongly disagree Disagree Unsure Agree Strongly agree

3) The dying person had some control over decision-making before dying

Strongly disagree Disagree Unsure Agree Strongly agree

4) There was a choice about place of death

Strongly disagree Disagree Unsure Agree Strongly agree

5) There was control about place of death

Strongly disagree Disagree Unsure Agree Strongly agree

6) Information was readily available to explain what was happening

Strongly disagree Disagree Unsure Agree Strongly agree

7) It was easy to obtain advice about managing the physical caring process

Strongly disagree Disagree Unsure Agree Strongly agree

8) If required, the dying person was able to request spiritual support

Strongly disagree Disagree Unsure Agree Strongly agree

9) Emotional support was available

Strongly disagree Disagree Unsure Agree Strongly agree

10) Hospice services were available

Strongly disagree Disagree Unsure Agree Strongly agree

The statements below focus on the last 24 hours of the dying person's life and the actual death itself. Please record your *immediate* response to the statements based on your experiences and observations by marking an X on the line under the word that matches your opinion most closely. There is no wrong or right answer, *please respond as you understood the situation to be*. If you are uncertain, indicate that this by responding Unsure. There is space provided at the end of the questionnaire for additional comments.

A) Specific requests the dying person may have had about practical aspects of the dying process were honoured

Strongly disagree Disagree Unsure Agree Strongly agree

B) There was time to say goodbye

Strongly disagree Disagree Unsure Agree Strongly agree

C) There was some control over the timing of the death

Strongly disagree Disagree Unsure Agree Strongly agree

D) The dying person's life ended naturally and was not unnecessarily prolonged

Strongly disagree Disagree Unsure Agree Strongly agree

E) Pain control was adequate

Strongly disagree Disagree Unsure Agree Strongly agree

F) Other physical symptoms were well managed

Strongly disagree Disagree Unsure Agree Strongly agree

G) The dying person had a choice about who was present at the moment of death

Strongly disagree Disagree Unsure Agree Strongly agree

H) The death took place in sufficient privacy

Strongly disagree Disagree Unsure Agree Strongly agree

I) The death was dignified

Strongly disagree Disagree Unsure Agree Strongly agree

Concluding question:

If a person's death could be described as "good" do you think that the dying person would have described this as a Good Death?

Yes

No

Not sure

In your own words, how would you define a Good Death? (You may use as few or as many words as you choose)

Please use this space for an extra thoughts or observations you would like to include. If you would like personal contact, then please provide your name and preferred contact details here.

Many thanks for your time, your honesty and your reflections.

Clare Manicom
Oncology social worker
clare.manicom@cancercare.co.za
0861 99 99 14

APPENDIX C POSTAL QUESTIONNAIRE

October 2011, Rondebosch

You may have met me at GVI Oncology, Constantiaberg, while your family member or friend was receiving care for their cancer. I am the social worker attached to this unit. I am undertaking this study as part of my Masters Degree in Social Work at the University of Cape Town. My study examines where patients died and how their death was experienced by those identified as “next of kin” when the patient first registered at our practice. Information gathered will help medical teams to better understand the experiences and needs of dying patients and those involved in their care.

It is understandable that reflecting on the death of someone you cared about may evoke emotional responses so you are welcome to provide your contact details if you would like bereavement counselling at no cost to yourself. I do not need your name but would appreciate some basic information being completed in addition to answering some questions below. If you would rather not complete this questionnaire, please be so good as to return it to me in the enclosed envelope, even if it is blank or partially completed.

The questionnaire should take less than 10 minutes to complete, and should be returned in the envelope enclosed before the end of November 2011.

Please provide some basic details, by marking the appropriate box with an X:

1) Your relationship to the deceased person?

Partner/spouse Parent Child Other relative Friend

Other relationship – please specify: _____

2) Please indicate that person’s (approximate) age when they died _____

3) Indicate the deceased’s sex? Male Female

4) What type of cancer did they have when they first came to the oncology practice?

Bladder Melanoma

Brain Ovary

Breast Pancreas

Colon or rectum Prostate

Lung Stomach (gastric)

Not sure Other – please specify: _____

5) Where did they die?

At home At Constantiaberg Medi-Clinic In another place (specify) _____

6) The (approximate) date of their death? _____

7) Would you describe yourself as being the main carer for the person who died?

Yes No Not sure

8) Was anyone employed to help with nursing care for the deceased at home during the last month of life?

Yes No Not sure

9) Was anyone present at time of death?

Yes No Not sure

10) If you answered Yes to the question above, who was present at the time of death?

Spouse or life partner Parent
 Child Sibling
 Other relative Member of medical staff or Hospice team
 Religious leader Friend

Other – please specify _____

The following statements focus on the last week of the dying person's life. Please record your *immediate* responses to the statements based on your experiences and observations, by marking an X on the line under the word that matches your opinion most closely. There is no wrong or right answer, *please respond as you understood the situation to be*. There is space provided at the end of the questionnaire for additional comments.

11) I understood that the person was dying

Strongly disagree Disagree Unsure Agree Strongly agree

12) I was able to choose the people involved in the caring process

Strongly disagree Disagree Unsure Agree Strongly agree

13) I knew where to get advice about managing physical care

Strongly disagree Disagree Unsure Agree Strongly agree

14) Spiritual support was available to me if I needed it

Strongly disagree Disagree Unsure Agree Strongly agree

15) Emotional support was available for me

Strongly disagree	Disagree	Unsure	Agree	Strongly agree
-------------------	----------	--------	-------	----------------

16) Assistance from St Luke's Hospice was available

Strongly disagree	Disagree	Unsure	Agree	Strongly agree
-------------------	----------	--------	-------	----------------

17) The dying person's preferred place of death was discussed with me in advance

Strongly disagree	Disagree	Unsure	Agree	Strongly agree
-------------------	----------	--------	-------	----------------

18) The person died in the place of their choice

Strongly disagree	Disagree	Unsure	Agree	Strongly agree
-------------------	----------	--------	-------	----------------

The statements below focus on the last 24 hours of the dying person's life and the actual death itself. Please record your *immediate* response to the statements based on your experiences and observations by marking an X on the line under the word that matches your opinion most closely. There is no wrong or right answer, *please respond as you understood the situation to be*. There is space provided at the end of the questionnaire for additional comments.

19) I was able to say goodbye in time

Strongly disagree	Disagree	Unsure	Agree	Strongly agree
-------------------	----------	--------	-------	----------------

20) I was prepared for the death

Strongly disagree	Disagree	Unsure	Agree	Strongly agree
-------------------	----------	--------	-------	----------------

21) The dying person's life ended naturally and was not unnecessarily prolonged

Strongly disagree	Disagree	Unsure	Agree	Strongly agree
-------------------	----------	--------	-------	----------------

22) Pain control was adequate at the end

Strongly disagree	Disagree	Unsure	Agree	Strongly agree
-------------------	----------	--------	-------	----------------

23) Other physical symptoms were well managed

Strongly disagree Disagree Unsure Agree Strongly agree

24) The dying person had indicated who they would like to be present at the time of death

Strongly disagree Disagree Unsure Agree Strongly agree

25) The death took place in an appropriate setting

Strongly disagree Disagree Unsure Agree Strongly agree

26) The death was dignified

Strongly disagree Disagree Unsure Agree Strongly agree

Please give your own responses to the questions below, remembering that there are no correct or incorrect answers:

27) Overall, how did you experience this person's death?

28) How would you describe a Good Death?

29) If a person's death could be described as "good" do you think that the dying person would have described this as a Good Death?

€Yes

€No

€Not sure

Please use this space for an extra thoughts or observations you would like to include. If you would like personal contact, then please provide your name and preferred contact details here.

Completion of this questionnaire is entirely voluntary.

Thank you for your time, your honesty and your responses.

Clare Manicom (Oncology Social Worker)

clare.manicom@cancercare.co.za

0861 99 99 14

APPENDIX D
Raw data – Basic details

Question	Response	CD	HD	Total
1	Partner/spouse	21	28	49
	Parent			
	Child	3	5	8
	Other relative			
	Friend		1	1
	Total	24	34	58
2	20-35	1		1
	36-50	1	2	3
	51-65	10	10	20
	66-80	12	15	27
	81+		6	6
	No response		1	1
	Total	24	34	58
3	Male	13	20	33
	Female	11	14	25
	Total	24	34	58
4	Bladder	1		1
	Brain		1	1
	Breast	2	3	5
	Colo-rectal	4	6	10
	Kidney	1		1
	Leiomyosarcoma		1	1
	Lung	5	7	12
	Lymphoma		1	1
	Melanoma	3	2	5
	Multiple myeloma		1	1
	Neuro-endocrine	1		1
	Non-Hodgkins			
	Lymphoma		1	1
	Oesophagus	2		2
	Ovary		3	3
	Pancreas	1		1
	Prostate	3	3	6
	Stomach		2	2
	Not sure		2	2
	Other	1	1	2
	Total	24	34	58

<u>Question</u>	<u>Response</u>	<u>CD</u>	<u>HD</u>	<u>Total</u>
5	Home		34	34
	Constantiaberg	24		24
	Other			
	Total	24	34	58
6	12 to 17	9	4	13
	18 to 23	6	6	12
	24 to 29	2	6	8
	30 to 36	3	12	15
	More than 36	4	6	10
	Not known/no response	0	0	0
	Total	24	34	58
7	Yes	22	26	48
	No		5	5
	Unsure	2	3	5
	Total	24	34	58
8	Yes	4	17	21
	No	19	17	34
	Unsure			
	No response	1		1
	Total	24	34	58
9	Yes	22	33	55
	No	0	1	1
	Unsure	2		2
	Total	24	34	58
10	Spouse or life partner	15	25	
	Parent	1	2	
	Child	8	13	
	Sibling	2	6	
	Other relative	6	7	
	Member of medical staff	5	11	
	Minister of religion	1	2	
	Friend	2	6	

Raw data continued - Last week

<u>Question</u>	<u>Response</u>	<u>CD</u>	<u>HD</u>	<u>Total</u>
11	1 Strongly disagree			
	2 Disagree	2		2
	3 Unsure	3	5	8
	4 Agree	9	11	20
	5 Strongly agree	10	17	27
	6 No response		1	1
	Total	24	34	58
12	1 Strongly disagree	1		1
	2 Disagree	5	5	10
	3 Unsure	3	1	4
	4 Agree	8	13	21
	5 Strongly agree	5	15	20
	6 No response	2		2
	Total	24	34	58
13	1 Strongly disagree	1		1
	2 Disagree	2		2
	3 Unsure	3		3
	4 Agree	14	20	34
	5 Strongly agree	3	13	16
	6 No response	1	1	2
	Total	24	34	58
14	1 Strongly disagree			
	2 Disagree	3		3
	3 Unsure	2		2
	4 Agree	16	18	34
	5 Strongly agree	3	15	18
	6 No response		1	1
	Total	24	34	58
15	1 Strongly disagree	2		2
	2 Disagree	3	2	5
	3 Unsure	1		1
	4 Agree	10	14	24
	5 Strongly agree	7	18	25
	6 No response	1		1
	Total	24	34	58

<u>Question</u>	<u>Response</u>	<u>CD</u>	<u>HD</u>	<u>Total</u>
16	1 Strongly disagree	1		1
	2 Disagree	2	2	4
	3 Unsure	2	1	3
	4 Agree	5	15	20
	5 Strongly agree	10	15	25
	6 No response	4	1	5
	Total		24	34
17	1 Strongly disagree	6	1	7
	2 Disagree	9	8	17
	3 Unsure	1	2	3
	4 Agree	4	8	12
	5 Strongly agree	1	14	15
	6 No response	3	1	4
	Total		24	34
18	1 Strongly disagree	4		4
	2 Disagree	4		4
	3 Unsure	8	2	10
	4 Agree	3	9	12
	5 Strongly agree	2	21	23
	6 No response	3	2	5
	Total		24	34

Raw data continued - Last 24 hours

<u>Question</u>	<u>Response</u>	<u>CD</u>	<u>HD</u>	<u>Total</u>
19	1 Strongly disagree			
	2 Disagree	2	7	9
	3 Unsure	3	3	6
	4 Agree	9	10	19
	5 Strongly agree	10	13	23
	6 No response		1	1
	Total	24	34	58
20	1 Strongly disagree	1		1
	2 Disagree	1	2	3
	3 Unsure	3	7	10
	4 Agree	13	16	29
	5 Strongly agree	6	9	15
	6 No response			
	Total	24	34	58
21	1 Strongly disagree	1		1
	2 Disagree	1	1	2
	3 Unsure	2	3	5
	4 Agree	11	16	27
	5 Strongly agree	9	14	23
	6 No response			
	Total	24	34	58
22	1 Strongly disagree	1	4	5
	2 Disagree	1	4	5
	3 Unsure	3	12	15
	4 Agree	15	13	28
	5 Strongly agree	4	1	5
	6 No response			
	Total	24	34	58
23	1 Strongly disagree	2		2
	2 Disagree	1		1
	3 Unsure	3	7	10
	4 Agree	14	18	32
	5 Strongly agree	3	9	12
	6 No response	1		1
	Total	24	34	58

<u>Question</u>	<u>Response</u>	<u>CD</u>	<u>HD</u>	<u>Total</u>
24	1 Strongly disagree	5	2	7
	2 Disagree	6	17	23
	3 Unsure	5	7	12
	4 Agree	4	3	7
	5 Strongly agree	2	5	7
	6 No response	2		2
	Total		24	34
25	1 Strongly disagree	2		2
	2 Disagree	1		1
	3 Unsure	1	1	2
	4 Agree	16	14	30
	5 Strongly agree	3	17	20
	6 No response	1	2	3
	Total		24	34
26	1 Strongly disagree			
	2 Disagree	1	1	2
	3 Unsure	4	3	7
	4 Agree	12	13	25
	5 Strongly agree	6	16	22
	6 No response	1	1	2
	Total		24	34
29	1 Yes	12	17	29
	2 No	6	1	7
	3 Unsure	6	12	18
	4 No response		4	4
	Total	24	34	58