EXPLORING WHETHER THE NEEDS OF DYING PATIENTS IN PRIVATE SECTOR HOSPITALS ARE BEING MET

by

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ABSTRACT

As palliative medicine is an area only beginning to develop as a speciality in South Africa, it was felt that an investigation into the situation with regard to dying patients in our own private sector hospitals was needed.

The objectives were to ascertain whether patient and family needs are met as a means of an index of quality of care and to identify domains of care where improvement is needed most. The validated 'After death Bereaved Family Member Interview' from the questionnaire for hospital purposes, as part of the Toolkit of Instruments to Measure End-of-life Care (T.I.M.E.), was used as research instrument with the permission of the author Dr JM Teno. Domains that were investigated include the following: physical comfort and emotional support of the patient; focused attention on the individual patient; encouragement of advanced care planning; information and promotion of shared decision-making; care plan; provision of coordinated care of health professions; emotional and spiritual support of the family; and an overall rating for patient focused, family centred care.

As a descriptive study with limited numbers this study cannot make any conclusive claims with regard to the care that all terminal patients receive in private hospitals in Port Elizabeth. Results indicate that the single domain with most opportunity to improve for both the oncology group and the general group is attention to the family. The model of patient-focused family-centred care, which is applicable to palliative care, makes this an urgent opportunity for improvement in the care of the dying patients in private hospitals. Control of pain and other symptoms remains an important medical and ethical issue, indicated in this research as needing attention. Information and promotion of shared decision-making is the other domain that warrants attention. The fact
that domains with the least improvement opportunities are the focus on the individual and the coordination of the care makes sense if it is kept in mind that the research was done in private hospitals.

This investigation indicated that families are not in general unhappy about the care dying patients in private hospitals in Port Elizabeth received. Dying patients and their families, however, do have needs that are not currently being acknowledged and adequately met by the way they are managed in private hospitals. There is a definite need for palliative care in private hospitals, but the challenge is to get the medical fraternity to acknowledge that and accept palliative care as a much-needed service in private sector medicine. Practicalities of establishing palliative care in private practice in Port Elizabeth and in South Africa will make interesting material for future studies.

**Key Words:**

Palliative medicine; Unmet needs; Private hospitals; Toolkit project.
1 INTRODUCTION

1.1 INTRODUCTION

"If medicine takes aim at death prevention, rather than at health and relief of suffering, if it regards every death as premature, as a failure of today's medicine - but avoidable by tomorrow's - then it is tacitly asserting that its true goal is bodily immortality. Physicians should try to keep their eyes on the main business, restoring and correcting what can be corrected and restored, always acknowledging that death will and must come, that health is a mortal good, and that as embodied beings we are fragile beings that must stop sooner or later, medicine or no medicine." (Kass, 1980)

‘Palliative care’ is from the Latin word ‘palliare’ which means ‘to cloak or cover’. (Little, Fowler & Coulson, 1970) Palliative care is defined as the comprehensive, interdisciplinary care of patients and their families facing a terminal illness, focussing primarily on comfort and support. (Billings, 1998) Key aspects with regard to the patient self include meticulous symptom control, psychosocial and spiritual care and a personalised management plan that maximises patient-determined quality of life. As for the family members and loved ones, family oriented care extends through the process of care to the time of bereavement. The delivery of coordinated services is regarded as vitally important, especially at home, but also in hospital, extended care facilities, day care centres and specialised units. (Billings, 2000)

Palliative care has been described as a new medical speciality. It is actually not at all. It is probably the oldest. For centuries gone by physicians and nurses frequently had only palliation to offer for diseases like cancer. The
misunderstanding about the 'new speciality' arises because many doctors and nurses practising today were educated in an era of technologically sophisticated medicine when matters relating to the care of terminally ill, received little or no attention.

What is new, are the medical and scientific advances of the last few decades, which are of great benefit in the practice of palliative care. The medical care has been improved by better knowledge about the disease processes and the causation of symptoms, together with advances in pharmacology, surgery and radiotherapy. Add to this an improved understanding of the importance and optimal management of psychosocial, cultural and spiritual suffering associated with advanced disease, and it possible to provide comprehensive care for patients with advanced incurable diseases like cancer and AIDS, covering all aspects of their disease and suffering. This is modern palliative care. (Woodruff, 1999)

1.2 BACKGROUND TO PALLIATIVE MEDICINE

Contemporary palliative care has evolved beyond its origins as a protest against the quality of terminal care provided in acute hospitals in the 1960s. The British hospice model transformed terminal care internationally. (Glare, 1998) The evolution of modern inter disciplinary palliative care can be seen in five phases, which are not necessarily sequential or exclusive. (Woodruff, 1999) The important first phase was establishing inpatient hospice care providing comprehensive multidisciplinary care, including excellent medical care. The opening of St Christopher’s Hospice in London in 1967 by Dr Cicely Saunders was an important step in the hospice movement. “Hospice” developed as freestanding, independent units. The second phase developed together with the first one, namely development of a multidisciplinary domiciliary palliative care. This involved the patient’s own doctor and nurses trained in palliative care, who worked as part of a multidisciplinary palliative care team.
The success of St Christopher’s and other freestanding hospices, paved the way for the establishment of hospital-based hospices and hospice wards in general hospitals (third phase), making multidisciplinary palliative care available to many more terminally ill patients. This was a significant development as it acknowledged the need for multidisciplinary palliative care within the hospital system. This meant accepting the multidisciplinary palliative care back into ‘mainstream’ hospital medicine, as palliative care service personnel now worked alongside their colleges in mainstream medicine. Patients now could have the benefit of both acute care in a general hospital care, as well a palliative care input at the same time. (Woodruff, 1999)

Development of consultative palliative care services in general hospitals further increased the availability of palliative care in the fourth phase. This allowed earlier involvement of the palliative care team services and education by example. Patients now could be referred earlier, rather than only when all avenues of anticancer treatment were exhausted or when the medical aid funds were exhausted. Consultative services were more likely to receive referrals from doctors who wish to remain involved in a patient’s management.

The ultimate objective, the fifth phase, should be for all doctors, nurses and other health care professionals to understand and appreciate the essentials of inter-professional palliative care. This is an important stage, which is obviously more advanced in the developed countries. In the medical schools of many developed countries, palliative care is already an integrated part of the pre graduate studies and postgraduate courses in palliative care are offered. Billings & Pantilat, (2001) did a study on a random sample of 100 academic centres in the United States. Most programs were new, averaging four years of existence, and many were rudimentary. More over despite advances in attention to end – of - life care, about three quarters of hospitals still lacked a program. ‘If palliative care programs continue to be developed in academic
hospitals, we might anticipate in the near future a significant impact on clinical services of many young physicians and thus on many patients and families facing terminal illness', they concluded. We can also foresee a need for more well-trained faculty to staff these programs and teach house officers. The field of palliative care seems to be achieving a degree of legitimacy in the academic medical centres where future generations of doctors are training. (Billings & Pantilat, 2001) It will however, take a long time before the majority of health care professionals are educated about the needs of dying patients and their families, even longer in the less developed countries. (Woodruff, 1999)

Currently most palliative care teams are still multidisciplinary in nature. A hierarchical structure dominates thinking. In these teams, members practice independently of one another, each member being guided by his/her own professional standards. Profession hierarchy determines leadership, and with a classical hospice background, the leader is expected and accepted to be the matron. Each member reports to the team leader, either the matron or the physician and typically rigid role boundaries exist. In inter-professional or interdisciplinary teams members function interdependently. Each member is guided by professional practice standards and also by the team's practice standards. The problems and issues that arise in the patients' and families' care determine leadership. Roles and boundaries are flexible and teams vary in the extent to which they will allow patients to guide their practice. It is only by increasing our understanding of and respect for the abilities of all team members that interdisciplinary teamwork can evolve to improve the efficiency and the quality of the care we provide. (Ian Anderson module 11, 2002)

1.2.1 Hospital deaths

D Meier (2002) cited the work of Eric J. Cassell in: The nature of suffering and the goals of medicine. 'The relief of suffering and the cure of disease must be seen as twin obligations of a medical profession that is truly dedicated to the care of the sick. Physicians' failure to understand the nature of suffering can
result in medical intervention (though technically adequate) that, not only fails
to relieve suffering, but becomes a source of suffering itself.'

The hospital setting has strong emphasis on cure and the concept of
diagnosing dying is almost counter culture. Consequently, doctors are often
reluctant to diagnose dying. Instead they feel that there must always be
additional investigations or treatments to make the patient 'better'. This attitude
can be very destructive. The patients and family / carers are led to believe that
improvement is possible or likely. When the patient then deteriorates and dies,
the family may be left with a feeling of betrayal and loose trust in the health
care professionals. The patient's death can appear unexpected and his
relatives unprepared, often expressing the wish that they had been warned –'if
only someone told us'. (Ellershaw, 2001)

As in other aspects of medical care, the diagnosis of dying is a
combination of science and art. If we believe that the patient is in the dying
phase, then we should care for the patient and family appropriately. One of the
great barriers to diagnosing dying, is that health care professionals may not
know what to do next for dying patients and therefore continue active
treatment. (Ellershaw, 2001) Recent studies indicate not only that doctors seem
reluctant to speak about death, but also that they are inaccurate and
systematically optimistic about the future, thus delaying timely sharing of
information and referral to palliative care services.

Hospitals are traditionally structured for efficient treatment of acute
illnesses and exacerbations of chronic diseases. Health related quality of life
as defined by enhancing and preserving function might not be applicable for the
dying person. Individualized goals are needed for all patients, but this is
especially true for the dying person. (Teno, Byock & Field, 1999) When it
becomes clear that cure is no longer a realistic goal, the hospital structure often
fails to provide alternatives. Even if there is no reasonable chance of
meaningful recovery, treatment focussed on prolongation of life may continue
to the very moment of death. (Middlewood, Gardner & Gardner, 2001) Life-
prolonging medical care at the end of life may result in unnecessary suffering
for the patient and may also create emotional strain and financial difficulty for
the loved ones. (Covinsky et al, 1994)

Another essential difference between acute care and palliative care is that
the family and those who care for the patient assume a more important role in
the latter case. The World Health Organisation recognises this in its definition
that ‘the goals of palliative care is achieving the best possible quality of life for
the dying patient and their families’. (World Health Organisation, 1990) For the
dying this construct must be expanded to encompass the important role of the
family, namely medical care for the dying should be patient focussed and family
centred. “Patient focused” care recognises that the main emphasis of care
must be on meeting the patient’s needs and expectations, while “family
centred” care recognises the important role the family plays in the dying
patient’s care, as well as the important needs of the family members, including
help in adjusting to life after the death of a loved one. (Teno, Casey & Welsh,
2001)

Numerous recent studies confirm earlier observations that dying patients
and their families experience a wide range of unmet needs, while receiving very
costly care in hospitals. One large US study, SUPPORT, (Study to Understand
Prognosis and Preferences for Outcomes and Risks of Treatments, 1995)
underscores many of these problems. This investigation enrolled 9015 patients
who were admitted to academic hospitals with common, severe medical
conditions and who had a median survival of six months. Considerable
suffering and inappropriate use of resources were observed. Many patients
died in pain or with high ‘symptom burdens’. (Desbiens & Wu, 2000) Family
members often experienced social and financial devastation – having to quit a
job or suffering major losses of income or savings – because of the illness.
Phase 1 of this study confirmed substantial shortcomings in the care for
seriously ill hospitalised patients. To the researchers' shock and
disappointment, phase 2 interventions ineffective in changing communication,
decision-making and treatment patterns despite evidence that counselling and
information were delivered as planned. The conclusion was that that the
intervention may have failed to have an impact because strong psychological
and social forces underlie present practices. It was suggested that system-level
innovation and quality improvement in routine care might offer more powerful
opportunities for improvement. (The SUPPORT principle investigators, 1995)

When the patient enters the dying phase, an active process of care for
both the patient and the family / carers should be initiated. Paradoxically,
particularly in hospital settings, staff may withdraw at this point in time. The
active process of care includes reviewing the patient’s medication. Non-
essential drugs are discontinued and appropriate medication is prescribed with
consideration of the route of administration. The relatives are made aware that
the patient is dying and the religious and spiritual needs of the patient are
addressed. It is important that the patient's condition be reviewed on a regular
basis, with observations of symptom control and appropriate action taken, if
required. (Ellershaw, 2001)

1.2.2 Developed versus less developed countries

Palliative care services in developed countries include inpatient and
outpatient care, day therapy, bereavement counselling and a specialist
advisory role in both community and hospital settings. This clinical activity is
supported by education and research activities. It may offer all these elements,
but may also focus on specific areas. The tendency is toward integrated
palliative care teams based in general hospitals. These teams receive referrals
from general practitioners and specialists, general hospitals, old age homes;
frail care units, etc. Interdisciplinary teams manage patients, with regular
feedback to the referring parties. (Ian Anderson module 11, 2002)
The concept of palliative care in developed countries, as hospital-based programs, to care for the seriously ill and dying patients is growing as we see in multiple recent studies. (Weissman 2001; Billings & Pantilat 2001; Pan et al, 2001) The physician assisted suicide debate has sensitised health professionals and the public to the unmet needs of seriously ill and dying patients and helped to bring into focus the serious lack of resources outside of hospice care. Should palliative care teams be able to place themselves inside acute care hospitals, a win-win situation is created, where all involved parties could benefit from co-operation in challenging times. Hospital-based palliative care teams do have an essential role in improving end of life care and they will continue to do so for a few good reasons. Hospitals remain a common site of death; it is a known universal site of medical care for seriously ill and hospitals will remain an important factor for educational purposes.

Clinical benefits of having hospital-based palliative care teams include reduced pain and symptom burden for terminally ill patients. Hospitalised patients with incurable illnesses have complex needs, which go beyond pain management. These needs must be addressed if patients are to receive optimal medical care. Multiple interventions are needed, and amongst other things also multiple consultations for symptom control and counselling. (Manfredi, Morrison, Morris, Goldhirsch, Carter & Meier, 2000)

Financial benefits may be realised when costly, prolonged hospital and ICU stays and expensive tests preceding death are avoided. If the managing team, the patient and family acknowledge the fact that a patient is dying, terminally ill or incurable, management should be adapted to suit the patient’s wishes and realistic goals. Many unnecessary investigations and admissions to inappropriate, usually extremely expensive wards can be avoided without any negative effects on patient quality of life. On the contrary, their quality of life may significantly be improved by appropriate palliative care. Studies of varied
palliative care interventions point to cost savings. (Axelsson & Christensen, 1998)

The educational process and program that is undertaken around the role of the palliative care service impacts on the understanding of all health care professionals. The knowledge, skills and attitude gained during the implementation of palliative care program will have an influence on the care of patients earlier in their disease, including improvements of symptom control and communication skills. Frequently the experience of palliative care teams is that following the introduction of a palliative care plan, or a ‘care pathway’, health care professionals use the team more appropriately. (Ellershaw, 2001)

An evaluative study was done on the impact of 16 hospital-based palliative care teams based in US, UK, Canada and Belgium. These were mostly uncontrolled studies and multiple assessment instruments were employed. Positive effects included improved physical symptoms and improved satisfaction with care received. Psychosocial symptoms proved to be more refractory. Decreased hospital cost was demonstrated and better resource utilization was possible. (Francke, 2000)

Very little literature is available for the less developed countries. Very few patients have the luxury of being helped by palliative care practitioners, be it a handful of specialists, generalists or nurses with an interest in palliative medicine or other non-medical professionals. Most support organisations will only provide supportive care, and not palliation of symptoms. (Merriman & Keller, 2002) People die with unmet needs and unfinished business.

In Uganda, a major factor influencing the ministry of health is the fact that members of the ministry had terminally ill family members with AIDS suffering from unrelieved pain. Once they saw what could be done in terms of symptom
control, they were convinced of the value of palliative care. Uganda is the only African country with a five-year health plan including palliative care as an essential clinical service. In most African countries morphine is still illegal, so one of their very first battles is to get it legalised. (Merriman & Keller, 2002) Dr Anne Merriman, who developed a palliative care model initiative in Africa, did groundbreaking work in Uganda. The aim was to develop a system of providing palliative care that was suitable to African needs, affordable to people and culturally acceptable. This could be used as an example that could inspire and encourage palliative care efforts throughout the African continent. Through their action and example the skills and knowledge would spread. The majority of their patients are managed as home care patients in order to meet the practical and cultural needs of the community. In Kampala patients would be seen in hospital first if they were admitted, symptoms would be controlled and they would be followed up at home after discharge. (Merriman & Keller, 2002)

1.2.3 South African Perspective

We do not at this stage have, any specialists in this field in South Africa. As far as can be established, we do not have any coordinated palliative care programs in South Africa in either private or public sector hospitals. Physical needs are seen to by a selection of health care workers. Individuals, private organisations, churches and non-government organisations offer a variety of counselling services. Private oncology units are appointing social workers as counsellors as part of their multidisciplinary teams.

Specific clinical palliative work is currently mainly done through the hospice by way of in-patient units and home care programs. While hospice is programmed to holistically care for the terminally ill patients, they face serious limitations in what they can do. Financially hospice is not independent (The hospice movement in South Africa, 2000) and has to rely heavily on sponsorships (more readily available these days, especially from overseas donors for AIDS related projects) and funding from government. (Many different
most worthy projects are competing for funding from the same sources.) The traditional freestanding, independent hospices are unable to meet all the needs of growing numbers of terminally ill patients in our country. Being placed away (physically) from the action of mainstream medical care puts them at a disadvantage in that resources (beds, nursing staff, medical staff, administration and funding, to name but a few) cannot be shared. For the country as a whole there are 30 hospices of which only 13 have in-patient facilities. Some hospices do have access to government hospital beds and a small percentage of terminally ill patients are managed in this way. (The hospice movement in South Africa, 2000) Clearly with the HIV/AIDS epidemic and thousands of cancer patients, the situation is overwhelming and current facilities and structures are hopelessly inadequate. Acute care hospitals do have all the potential and infrastructure to provide good quality care. If only palliative care could be integrated into that system.

As far as education is concerned South Africa can once again definitely be counted with the less developed countries. Only a very small proportion of medical practitioners, nurses and other non-medical professionals have been exposed to the principles of palliative care. This study is part of the MPhil in Palliative Medicine degree through University of Cape Town, the first postgraduate course offered in South Africa. Some medical schools include a limited palliative care module in the curriculum of undergraduate medical students. There is a diploma in palliative care for nurses that can be obtained by doing a one-year course offered through some of the local hospices. (The hospice movement in South Africa, 2000)

It is clear from the above five stages of development of palliative care, that palliative care in South Africa is indeed poorly developed. With the resources and health care needs that we have in our country, home care will always have to be the option catering for the majority of our terminally ill patients. Admissions to hospitals, hospices or other units of care can only meet
a small fraction of the need. Through a study like this, however, the needs of the terminally ill can be highlighted. The stakeholders need to be sensitised to the needs of dying patients and their families. If physicians, in particular, do not recognise the unmet needs of dying patients, unnecessary suffering will continue.

1.3 AIM AND OBJECTIVES OF THIS STUDY

The aim of this study is to establish whether the needs of dying patients are being adequately met in the private hospital sector in Port Elizabeth.

The objectives are twofold: first to ascertain whether both patient and family needs are met by means of an index of quality of care. The second objective was to identify areas where improvement in care at the end-of-life is needed most, should there be indications from results that care is indeed not optimal. An overall rating for patient focussed, family centred care was also done to get an idea of the perception of family members of the different domains and overall care received at the hospital.

The following domains were explored:

i) Physical comfort and emotional support of the patient;

ii) Focused attention on the individual patient;

iii) Encouragement of advanced care planning;

iv) Promotion of shared decision-making re care plan;

v) Provision of coordinated care of health professions;

vi) Emotional and spiritual support of the family.
As palliative medicine is an area only beginning to develop as a speciality in South Africa, it was felt that we needed to investigate the situation in our own private sector hospitals before one can address our unique challenges. Results of this investigation will indicate if needs of dying patients are currently being acknowledged and adequately met by current way dying patients are managed in private hospitals.
2 RESEARCH DESIGN AND METHODOLOGY

This chapter will examine the research design and methodology of the study. The following areas will be discussed: the design, method, the participants and sampling procedure, the research procedure and the data analysis techniques.

2.1 RESEARCH DESIGN

A descriptive, exploratory cross-sectional study was done, investigating the quality of care patients received in the last days of their lives in private hospitals.

2.1.1 The participants: sampling procedure.

All adult deaths in each of the three private hospitals (St George’s and Mercantile Hospitals, both from the AFROX group and Greenacres Hospital from the NETCARE group) in Port Elizabeth during the month of April 2002 were recorded. The aim was to specifically record deaths that were due to known, expected, natural causes. Possible respondents were identified and certain exclusions were made as described below. Bereaved family members were phoned three to four months after the death of the patients. For the purpose of the discussion of this study, all respondents are referred to as family members, although some interviews were done with friends.

Patients excluded from the study were the following:

i) Patients who died unnatural or unexpected deaths.

ii) Patients under the age of 18 years.

iii) No interviews were done with family members under the age of 18 years.
iv) Physicians preferred for some patients and relatives to be excluded for personal and psychological reasons. These recommendations were accepted without questioning or further investigating.

2.1.2 Procedure

The research was done in the form of after-death telephonic interviews with bereaved family members. Hospital administrators identified deaths during the month of April 2002 from the records and extracted next of kin data. They wrote to medical practitioners to screen suitability of patients for the study and to get consent to approach next of kin to participate in the study. (Appendix 1) If the medical practitioners agreed that the patients were suitable for the study, the hospital administrators wrote letters to next of kin. (Appendix 2) If next of kin did not phone to refuse an interview, a representative of the hospital administrators phoned them in a follow up to the letter to ask their consent to be interviewed. Participants were asked to give informed consent, while their privacy and confidentiality were assured. Participants were granted the right to refuse participation. The hospital administrator's representative could be approached for more information on the study and could be notified if the person preferred not to participate in the study. No one was coerced and it was pointed out at every stage that participation was voluntary.

Consent to participate was discussed at the start of the telephonic interview. (Appendix 3) If participants indicated that they wish not to participate in the study by phoning the available telephone number of the representative of the hospital manager or not giving consent at the time of the initial phone call, no further contact was made. Once the participants agreed to be interviewed, an arrangement was made to phone them at a convenient time to complete the questionnaire.
The purpose of the study, as well as the procedure, risks and possible benefits were explained at the beginning of each interview. Respondents were reassured that they could access more information on the project (either through the researcher or the representative of the hospital manager).

A cover sheet containing the participant's detail, as well as a few questions confirming the detail of the deceased person, was completed for every participant. In cases where the next of kin, as reflected on the hospital admission information, was not, according to himself or herself, the best person (i.e. the person who knows most about the deceased person's care in the last few days), the person they suggested, was contacted.

The questions were written out in advance, and answers were mainly closed-ended. Questions were read word-for-word, giving respondents time to choose the applicable answer. The researcher did the interviews herself to minimise interviewer bias. If a respondent needed clarification about a question, the question was read again, avoiding interpretation of the question. If it was still not clear, the response was recorded verbatim.

Individual results were treated as strictly confidential. Computerised data were kept secure, (names were stored in one file, study number and personal data in another) Questionnaires were stored away from the workplace after completion, and were only being available to the researchers.

The Research Ethics Committee of the Health Sciences Faculty of the University of Cape Town approved the protocol.

2.1.3 Measures:

Toolkit of Instruments to Measure End-of-Life-Care ('T.I.M.E.'), as developed by Dr Joan Teno MD, MS from the Centre for Gerontology and
Health Care Research, Brown University, Massachusetts, was used with the permission of the authors. The component used was the validated ‘After death Bereaved Family Member Interview’ from the questionnaire for hospital purposes (Appendix 4 Questionnaire) (Teno, Okun, Casey & Welsh, 2000)

The Toolkit of instruments to Measure End-of-Life-Care (‘TOOLKIT’ project) is a research effort with the goal of creating a measurement tool to allow health care institutions to evaluate their care of dying patients. Through measurement of current practice, institutions are enabled to clearly visualise where and how key processes can be adapted to provide truly patient centred, family focussed care for their dying patients. The goal was to have unambiguous questions that respondents are able and willing to answer in a consistent and accurate manner. The instrument was designed to capture how the process of dying is managed and focused on reporting objective facts and experiences, rather than the measurement of subjective states and participants. (Fowler, Coppola & Teno, 1999)

The domains for exploring were identified through both focus group discussions and a literature review. (Teno, Casey, Welsh, 2001) An important process that strengthen the patient focussed family centred care is information and education of both patient and family to the extent they want /need it. People differ greatly in the way they what and how much they want to know about the disease, it’s likely future course and their different tasks in living with the disease. Information and education must be adapted to what their needs in this regard. Very importantly, they must also be helped to understand what they can expect from the health care system they are they are using. Another equally important link to high quality end-of life-care is coordination and continuity of medical care. Patients and their families so often receive care from a variety of care providers and despite that, or may be because of that, feel abandoned in their hours of greatest need. Patient focussed family centred care cannot efficiently be provided if services are fragmented and
uncoordinated. These two aspects are included as domains in the questionnaire and overall rating scales give a idea of what family members thought of he overall care.

The domains identified as important in end-of-life care that are included in the questionnaire are the following:

i) Physical comfort and emotional support of the patient;
ii) Focused attention on the individual patient;
iii) Encouragement of advanced care planning;
iv) Promotion of shared decision-making re care plan;
v) Provision of coordinated care of health professions;
vi) Emotional and spiritual support of the family; and
vii) Overall rating for patient focussed, family centred care.

The part of the TOOLKIT that was used is the retrospective bereaved family member interview, which relies on a family member of the dying person’s perspectives to examine the quality of care that was provided during the last phase. This instrument provides the measurement tools to apply the principles of quality improvement in order to change key processes of care so that medical care for dying persons is truly patient focused and family centred. The questions proposed to measure each of these domains of care that the dying person and their families received during the time the dying person was in the care of the hospital.
<table>
<thead>
<tr>
<th>Domain</th>
<th>Objective</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Comfort and Emotional Support of patient</td>
<td>The dying persons discomfort is recognized and they receive their desired level of comfort, physically and emotionally.</td>
</tr>
<tr>
<td>Focus on The Individual</td>
<td>The dying person is treated with respect and dignity. This includes helping the patient achieve their desired level of control over their functioning and daily activities.</td>
</tr>
<tr>
<td>Advance Care Planning</td>
<td>Health care providers communicate and negotiate with the patient regarding goals of care and formulate plans, including contingency plans, so that their references are honoured.</td>
</tr>
<tr>
<td>Promotion of shared decision-making</td>
<td>Patients and their families are informed about their illness, its disease trajectory and prognosis. Medical decisions should reflect the patients' desired involvement and informed preferences.</td>
</tr>
<tr>
<td>Provision of coordinated care</td>
<td>Coordinated care is provided, no contradictions in explanations, enough information is available to treating medical personnel.</td>
</tr>
<tr>
<td>Emotional and spiritual support of the family.</td>
<td>The family receives the desired support at time prior to and after the patient’s death, including appropriate referral for bereavement services.</td>
</tr>
<tr>
<td>Overall ratings</td>
<td>Provision of patient-focussed family centred care</td>
</tr>
</tbody>
</table>
As a result of the different types of questions included in this questionnaire, there are four types of response categories, including:

i) Yes / no and yes / no / don’t know response options.

ii) 4-point scales ranging from always, usually, sometimes to never.

iii) 3-point scales ranging from ‘less than needed, more than needed to just the right amount.’

iv) Ratings on a scale from 1-10.

Examples of question types include the following:

1. An example of the yes/no questions is ‘During (patient’s) last few days in hospital was there enough help with medication and dressings?’ Yes will get a ‘0’, indicating that relatives were satisfied with the care the patients received. A ‘no’ on the other hand will get a ‘1’, indicating that there is room for improvement.

2. An example of the use of the 4-point scale is: ‘While (patient) was at (hospital), how often were you or other family members kept informed about (patient’s) condition – always, usually, sometimes, never?’ Any response other than ‘always’ is considered a problem or an opportunity to improve in that domain. Any answer that indicates an opportunity to improve is treated as a problem and is scored as ‘1’. An answer of ‘always’ will obviously score a ‘0’.

3. An example for the 3-point scale is the question: ‘During his/her last few days in hospital, did (patient) receive too much, too little or just the right amount of medication for his/her pain?’ Both too much and too little is scored with ‘1’, as it is regarded as an opportunity to improve, while just the right amount is scored with a ‘0’.
An example of a rating scale question is: ‘On a scale of 0 to 10 were where 0 means the worst possible care and 10 means the best possible care the next question is asked. ‘During his/her last few days in hospital, how well did the doctors, nurses and other professional staff that cared for (patient) communicate with him/her and the family about the illness and the likely outcomes of care?’ The code is the chosen number from 0 to 10.

2.1.4 Data analysis

2.1.4.1 Problem score

All answers in the domain questions were scored with either a ‘0’ or a ‘1’. Where family members indicated that they were satisfied with the care, the score of ‘0’ was recorded in that field. Whenever family members indicated that care could be improved or was sub optimal, a score of ‘1’ was given. For every question all the responses were added and then divided by the number of participants to give the ‘problem score’ with a range of 0 – 1. Thus, a high problem score is an indication of more opportunities to improve care. (Or reason for more concern about the quality of care.) Any answer that indicates an opportunity to improve is treated as a problem. A low score is an indication that family members generally regard the specific domain to receive satisfactory care.

The example of the domain of ‘focus on the individual’ will be discussed below.
Table 2. Questions of the 'focus on the individual' domain

<table>
<thead>
<tr>
<th>Question</th>
<th>Possible Answers</th>
</tr>
</thead>
<tbody>
<tr>
<td>D21. During his/her last few days, how often were [PATIENT’S] personal care needs - such as bathing, dressing, and changing bedding - taken care of as well as they should have been - would you say always, usually, sometimes, or never?</td>
<td>[ ] ALWAYS [ ] USUALLY [ ] SOMETIMES [ ] NEVER</td>
</tr>
<tr>
<td>D22. During his/her last few days, how often was (he/she) treated with respect by those who were taking care of (him/her) - always, usually, sometimes, or never?</td>
<td>[ ] ALWAYS [ ] USUALLY [ ] SOMETIMES [ ] NEVER</td>
</tr>
<tr>
<td>D23. During his/her last few days, how often was [PATIENT] treated with kindness by those who were taking care of (him/her) – always, usually, sometimes, or never?</td>
<td>[ ] ALWAYS [ ] USUALLY [ ] SOMETIMES [ ] NEVER</td>
</tr>
<tr>
<td>D24. During his/her last few days was there enough help available to meet (his/her) personal care needs, like bathing, dressing, feeding, and going to the bathroom?</td>
<td>[ ] YES [ ] NO</td>
</tr>
<tr>
<td>D25. During his/her last few days was there enough help with medications and getting dressings changed?</td>
<td>[ ] YES [ ] NO</td>
</tr>
<tr>
<td>E2. During his/her last few days, how often did you have concerns about [PATIENT’S] personal care needs – such as bathing, dressing, and changing bedding- being met when you were not there - always, usually, sometimes, or never?</td>
<td>[ ] ALWAYS [ ] USUALLY [ ] SOMETIMES [ ] NEVER</td>
</tr>
</tbody>
</table>

For the questions with 'always, usually, sometimes and never' answers, 'always' is scored with a '0', indicating that there is no problem. Any other answer to any of those questions is considered less than ideal; it is scored with
a 1, indicating that respondent identified an improvement opportunity. For those two questions with 'yes' or 'no' answers, a 'yes' is scored with a '0', while a 'no' is scored with a '1', indicating a possible area of improvement or a 'problem'.

2.1.4.2 Domain score

A domain score is the total of the problem scores across the questions included in that domain divided by the number of the survey questions in that specific domain. The range varies from 0 to 1. This is the sum of the responses to the individual questions within that domain that indicates opportunity to improve. It is also an indication of the percentage of family members that that they thought care in the specific domain could be improved.

Example of a domain score: (expanding on the above example of the focus on the individual) If the problem scores for the different questions for the combined group (Oncology and General) were 0.46+ 0.31 + 0.38 + 0.23 + 0.12 + 0.50 the domain score would be 0.33. This is an indication that 33% of family members thought care could be improved, and by implication, that 67% of family members were satisfied with care in this regard.

2.1.4.3 Scale scores

Scale scores, on the other hand, do not correspond directly with the opportunity to improve. Instead, the scale scores reflect the average answer to survey questions whose response categories range from a low response to a high response. (E.g. ratings are plotted on a scale from 0-10, where 0 means the worst possible care and 10 means the best possible care.)
### Table 3. Scale score questions

<table>
<thead>
<tr>
<th>Question</th>
<th>Rating Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>F1. During his / her last few days, how well did the doctors, nurses, and other professional staff who cared for [PATIENT] communicate with (him/her) and the family about the illness and the likely outcomes of care?</td>
<td>[0 – 10]</td>
</tr>
<tr>
<td>F2. During his / her last few days, how would you rate how well those taking care of [PATIENT] provided medical care that respected (his/her) wishes?</td>
<td>[0 – 10]</td>
</tr>
<tr>
<td>F3. During his / her last few days, how well did those taking care of [PATIENT] make sure (his/her) symptoms were controlled to a degree that was acceptable to (him/her)?</td>
<td>[0 – 10]</td>
</tr>
<tr>
<td>F4. During his / her last few days how well did those taking care of [PATIENT] make sure that [PATIENT] died with dignity - that is, died on (his/her) own terms?</td>
<td>[0 – 10]</td>
</tr>
<tr>
<td>F5. During his / her last few days how well did those taking care of [PATIENT] do at providing emotional support for you and [PATIENT’S] family and friends?</td>
<td>[0 – 10]</td>
</tr>
<tr>
<td>F6. On a scale of 0 to 10, where 0 means the worst care possible and 10 means the best care possible, what number would you give the overall care that [PATIENT] received in [PATIENT’S] last few days of life?</td>
<td>[0 – 10]</td>
</tr>
</tbody>
</table>

### 2.1.4.4 Family member interviews

It must be kept in mind that the field of palliative medicine by definition also includes the family. The World Health Organisation recognises this in its definition of the goals of palliative care as providing the best possible quality of life for the dying patients and their families (World Health Organisation, 1990).
Palliative care is based on the concept of being patient-centred and family-focused. Dying redefines the family member as a direct participant rather than just an agent for the patient. Care given to the patient strongly affects the well being of the family. (Steward, Teno, Patrick & Lynn, 1999)

It is true that only the patient can tell about his or her own quality of life, but, unless you can find ways to use proxies, you will never get any information on your weakest group of patients, because they may not be able to tell you. (Higgenson, 2000) Assessing the needs of the terminally group of patients and whether these needs are met is particularly difficult. It is extremely difficult to predict exactly when patients will die and sudden deterioration may prevent researchers to do the interview at a set time before death. Cognitive impairment, communication deficits and severe stress caused by symptoms, may make participating too burdensome physically or emotionally. (Sneeuw, Aaronson, Sprangers, Detmar, Wever & Schornagel, 1998; Teno & Coppola, 1999) These may be precisely the patients for whom information on quality of life is most needed for best clinical decision-making. Rather than loose all information on that patient, someone else, a family member or health professional, may be able to give some information. (Addington-Hall & Kalra, 2001)

It is true that family members cannot know exactly what a patient was feeling or thinking during those last few days, but they can report on their perceptions of the patient's dying experience and what they were told by the patients. They can also give their own observations and their own experience with the health care providers. Selecting the most suitable member to interview, rises an important issue, namely who is the best family member to act as a proxy for the patient's quality of care? It is probably the person who was most involved with the patient's care during all the phases of the dying experience and who would be able to answer most of the questions. (Fowler, Coppola, Teno, 1999) The difficulty of using bereaved family members as patients'
proxies are that information is indirect; proxies may be affected by the their own needs and problems and retrospective assessments may be altered by grief or difficulties to recall. (Higgenson, Priest & McCarthy, 1994)

Whether family members can be regarded as reliable proxies for the patient is a good question. Sneeuw, Aaronson, Sprangers, Detmar, Wever and Schornagel (1997) found that for patient populations at risk of deteriorating self-report capabilities, physicians and informal caregivers could be useful as alternative or complimentary sources of information on cancer patients’ quality of life. Better patient-proxy agreement was observed for more concrete questions, like daily activities and pain) (Sneeuw, Aaronson, Sprangers, Detmar, Wever & Schornagel, 1999) Retrospective assessments by bereaved family members should not be used as sole assessments of patients’ pain, anxiety or other symptoms. (Higgenson, Priest & McCarthy, 1994)

Although ratings by proxies provide less than perfect representation of patients’ experiences there seem to be sufficient agreement between their assessments of quality of life to make the information that proxies provide useful when the patient cannot be asked directly. (Sprangers & Aaronson, 1992) The question is however not whether the family member’s report accurately reproduces the patient’s response, but that they are able to identify important opportunities to improve and enhance care of the dying. (Teno & Coppola, 1999)
3 RESULTS AND DISCUSSION

3.1 INTRODUCTION

Due to the sampling technique used and the size of the sample no generalizations can be made to the larger population. During the month of April 2002, 48 adults died in the three private hospitals in Port Elizabeth, thirteen were excluded from the study due to the exclusion criteria determined before the study was initiated. Four people refused to participate in the study and five of the patients did not have a contactable relative or friend in this country at the time the interviews were done. In total twenty-six interviews were done. (See Table 4)

Table 4. Participants

<table>
<thead>
<tr>
<th>Total adult deaths for April 2002</th>
<th>48</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients excluded from the study:</td>
<td>13</td>
</tr>
<tr>
<td>Traumatic deaths</td>
<td>6</td>
</tr>
<tr>
<td>Unexpected deaths</td>
<td>3</td>
</tr>
<tr>
<td>Physician's advice of excluding</td>
<td>4</td>
</tr>
<tr>
<td>No contactable relative or friend</td>
<td>5</td>
</tr>
<tr>
<td>Relative or friend refused to participate</td>
<td>4</td>
</tr>
<tr>
<td>Total number of interviews done</td>
<td>26</td>
</tr>
</tbody>
</table>
Results are presented in three categories.

i) Patients who died in the oncology ward, (Onc, \( n=3 \)). There is an oncology ward in only one of the hospitals. Family members of these patients will be named 'oncology group' for the purpose of this discussion.

ii) Those who died in the other wards, which include intensive care units, high care units and general medical wards of all three hospitals, (Gen, \( n=23 \)). These participants will be named 'general group' during discussion of the results of this investigation.

iii) And a combination of the two groups, (Onc + Gen, \( N=26 \)).

It must be kept in mind that this study is small and results are comparing a sample of three in the oncology group to twenty-three in the general group. The oncology group with only three participants is too small to be considered stable, but it does give interesting information with regard to the care patients received in their last few days. Due to the sampling technique used and the size of the sample no generalizations can be made to the larger population.

3.2 DOMAIN RESULTS AND DISCUSSIONS

This study was structured in such a way that results are presented for the six domains and rating scales in separate groups. In order not to loose continuity it was decided to present the results and discussion of the specific domain together. For each domain results are given in a table, followed by written text elaborating on the data in the table. This is then followed by a discussion of the results of that particular domain.

The interpretation of the domain scores is as follows: If the domain score is 0.3 or lower, it indicates that 30% or less of the relatives who were interviewed thought that care could be improved. This is regarded as
acceptable as it indicates that 70% of relatives are satisfied with the care. If the domain score is between 0.40 and 0.60 it is considered that there is room for improvement in care seeing that 40-60% of relatives thought care could be improved. If, however, the domain score is higher than 0.70, it is considered that the majority of relatives, more than 70%, thought that there was opportunity to improve. See Table 5 below and also see different domain Tables 6-11 with shaded areas to highlight results in every domain.

Table 5. Different domain scores and interpretations of potential values.

<table>
<thead>
<tr>
<th>Domain score</th>
<th>Interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td>0.30 or less</td>
<td>Indication that 70% or more participants are satisfied with care in this domain. This is regarded, for the purpose of this study to be 'acceptable'.</td>
</tr>
<tr>
<td>0.40 – 0.60</td>
<td>Indication that between 40% and 60% participants are satisfied with care in this domain, regarded for the purpose of this study as 'room for improvement'.</td>
</tr>
<tr>
<td>0.60 or more</td>
<td>Indication that more than 70% of participants thought care in this domain could be improved. For the purpose of this study this is regarded as a problem and as an 'opportunity for improvement'.</td>
</tr>
</tbody>
</table>
### 3.2.1 Physical comfort and emotional support

Table 6. Physical comfort and emotional support

<table>
<thead>
<tr>
<th>Question</th>
<th>Onc</th>
<th>Gen</th>
<th>Onc+Gen</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understandable explanation of pain</td>
<td>0.00</td>
<td>0.50</td>
<td>0.44</td>
</tr>
<tr>
<td>D12a: Medication</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D15: Pain sufficiently, appropriately treated</td>
<td>0.50</td>
<td>0.56</td>
<td>0.56</td>
</tr>
<tr>
<td>D15a: Conflicting info on pain medication</td>
<td>0.50</td>
<td>0.38</td>
<td>0.39</td>
</tr>
<tr>
<td>D16b: Sufficient help with breathing</td>
<td>0.50</td>
<td>0.39</td>
<td>0.40</td>
</tr>
<tr>
<td>D17b: Sufficient help with anxiety</td>
<td>0.67</td>
<td>0.60</td>
<td>0.63</td>
</tr>
<tr>
<td>Domain score (range 0 - 1)</td>
<td>0.43</td>
<td>0.49</td>
<td>0.48</td>
</tr>
</tbody>
</table>

With regard to the domain of physical and emotional comfort of the patient, 43% and 49% of the family members (Oncology and General groups respectively) reported that care could be improved. The questions assessed mainly pain and pain treatment, as well as the management of dyspnoea and anxiety. The question with the highest score for both groups (Oncology 0.67 and General 0.60) indicates that 67% and 60% of relatives for the Oncology and General groups respectively, thought that patients were not sufficiently helped with anxiety. It should be noted that for question D12a, the Oncology group obtained a score of 0.00. The reason being that, two relatives reported the patient understood the explanations about pain medication and one patient were reported as not having experienced a pain problem at all.
These results are similar to that of other studies. Ellershaw, Smith, Overill, Walker & Aldridge (2001) reported that the symptoms of pain, agitation and respiratory tract secretions were controlled in 54%, 48% and 55% of patients respectively. In a study conducted by Tolle, Tilde, Hickman & Rodenfeld (2000), it was found that 54% of hospitalised patients in the last week of life had moderate to severe pain. The SUPPORT (1995) study found that for 50% of the conscious patients, family members reported moderate to severe pain at least 50% of the time. Lichter and Hunt (1990) reported that 51% of patients had pain in the last 48 hours of their lives, and that was more than ten years ago!

Although symptom control appeared inadequate in the domain section of the questionnaire, family satisfaction with regards to attention to symptom control was high, when assessed in the overall rating scales section. Scale scores for symptom control were 8.67 and 7.13 for the Oncology and General groups respectively. (See Table 13) These scores ranged from 0 to 10, with 0 being the worst possible care and 10 being the best possible care. Thus the results present an inconsistency similar to the results of Tolle's study (2000). Interestingly, 90% of the families in the Tolle study also reported 'that attention to comfort needs' were good or excellent, despite reporting symptoms in about 50% of the patients. Given the inherent limitations of the methods of assessment, these studies are better in assessing family perceptions than actual quality of care as experienced by the patient (Meyer, 2000).

Although patients suffer for many reasons, physicians can contribute substantially to the prevention or relief of suffering by controlling pain. (Chapman & Gavrin, 1999)

A pharmacist talking about his role in the interdisciplinary team said: 'I don't think there's another area that is quite so dramatic in terms of the
difference that the right drug therapy can make. Just to see the change in a person when the pain is gone or when the symptoms are under control. Then that person has time to talk to his family and to do the things that he has to do before he dies, or that he wants to do before he dies’. (Von Gunten, 2002)
3.2.2 Encouragement of advanced care planning

Table 7. Encouragement of advanced care planning

<table>
<thead>
<tr>
<th>Question</th>
<th>Onc n=3</th>
<th>Gen n=23</th>
<th>Onc+Gen n=26</th>
</tr>
</thead>
<tbody>
<tr>
<td>D2 Discussion about wishes re treatment</td>
<td>0.00</td>
<td>0.80</td>
<td>0.70</td>
</tr>
<tr>
<td>D3 Making sure care was consistent with wishes</td>
<td>0.33</td>
<td>0.76</td>
<td>0.71</td>
</tr>
<tr>
<td>D4 Treatment received consistent with wishes</td>
<td>0.33</td>
<td>0.43</td>
<td>0.42</td>
</tr>
<tr>
<td>Domain score (range 0 – 1)</td>
<td>0.22</td>
<td>0.66</td>
<td>0.61</td>
</tr>
</tbody>
</table>

Interesting to note is the variation in scores for the oncology and general groups (Domain scores: Oncology 0.22 and General 0.66). Relatives of the oncology group of patients reported much less opportunity to improve than the relatives of the general group patients. 78% of oncology relatives indicated that they were satisfied with the care in the domain of encouragement of advanced care planning. While the general group, 66% of relatives indicated that there was room for improvement. It seems as though there was not much discussion about wishes regarding their treatment in the general ward: 80% of relatives reported that the discussion of treatment wishes and making sure treatment was consistent with wishes (76%) needed to be improved. It is interesting to note that only 43% of the relatives reported that patients in this group received treatment that was inconsistent with their wishes.

For this domain, 80% of the families of Oncology ward patients were satisfied with the care received. However, for the families of General group
patients, only 34% indicated that they were satisfied with the care in this domain. This compares well with the SUPPORT study (1995), where 40% of patients in the intervention group reported that their preferences with regards to cardio pulmonary resuscitation (CPR) specifically, were discussed. Of those patients who did not discuss their preferences (60%), 41% indicated that they would have liked the topic to be discussed. Further, 20% of the intervention patients changed their resuscitation preferences to forgo CPR by the second week after enrolment and 41% of the intervention patients reported having a discussion with their prognosis with a physician. Of those who did not discuss prognosis, 42% of the intervention patients indicated that they would like to have such discussions (SUPPORT original, 1995).
### 3.2.3 Attention to emotional and spiritual needs of family

Table 8. Attention to emotional and spiritual needs of family

<table>
<thead>
<tr>
<th>Question</th>
<th>Onc</th>
<th>Gen</th>
<th>Onc+Gen</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=3</td>
<td>n=23</td>
<td>N=26</td>
</tr>
<tr>
<td>E4 Sensitive and sufficient discussion about relative’s beliefs</td>
<td>0.67</td>
<td>0.91</td>
<td>0.88</td>
</tr>
<tr>
<td>E6 Emotional support for the relatives</td>
<td>1.00</td>
<td>0.74</td>
<td>0.77</td>
</tr>
<tr>
<td>E7 Discussions about bereavement</td>
<td>0.67</td>
<td>0.78</td>
<td>0.77</td>
</tr>
<tr>
<td>E8 Counsellor suggested</td>
<td>0.33</td>
<td>0.96</td>
<td>0.88</td>
</tr>
<tr>
<td>Domain score (range 0 – 1)</td>
<td>0.67</td>
<td>0.85</td>
<td>0.83</td>
</tr>
</tbody>
</table>

This is the domain with the highest indication that there is opportunity for improvement for both groups. The conceptual model of patient-focused family-centred care is the basis of the questionnaire used. When a patient is in the dying phase of his/her life, the ‘unit of care’ is redefined to include the family. Results indicated that 67% of the family members of the Oncology group and 85% of the family members of the General group identified that they thought care could be improved. One would have expected the Oncology group to do better in this domain, because a larger percentage of their patients are considered to be suffering from terminal diseases. By the time a patient is terminally ill, a deep, strong bond often exists between patients and their Oncology team members. This is the kind of a situation where relatives may or may not be included in the relationship. They may find themselves having to build a relationship with the team and face losing a loved one to death at the
same time. Almost 70% of family members thought this could be improved. In the General group 85%, of family members thought care in this regard could be improved. This is not unexpected, as family members are not traditionally considered to be part of the treatment plan of patients in acute care situations.

In the Oncology group, 100% of relatives reported that emotional support for the relatives could be improved. The specific question was "During his/her last few days how much support in dealing with your feelings about [PATIENT'S] death did the doctors, nurses, and other professional staff taking care of (him/her) provide you - less support than was needed or about the right amount?" Less than needed was scored with a 1, indicating that this aspect could be improved.

Only three relatives of the oncology group were interviewed, all indicting that they needed more attention for their own feelings with regard to the patient's death. A problem score of 0.67 in the Oncology group indicated that the majority of the relatives (67%) felt that discussions about bereavement and their spiritual and religious beliefs could be improved.

In the General group, 96% of relatives (problem score of 0.96) reported that medical personnel did not suggest someone they could go to for help if stressed. In addition, 91% felt that their own religious and spiritual beliefs were not discussed sensitively and appropriately (problem score of 0.91). With regards to discussions on bereavement, 78% of the relatives reported that improvement was needed and 74% reported that emotional support for the relatives could be improved (Problem scores: 0.78 and 0.74, respectively).

‘Often the most effective intervention that we can offer is time spent with patients and family, listening to concerns and acknowledging their value...’ (McCue, 1995)
### 3.2.4 Information and promotion of shared decision-making

Table 9. Information and promotion of shared decision-making

<table>
<thead>
<tr>
<th>Question</th>
<th>Onc n=3</th>
<th>Gen n=23</th>
<th>Onc+Gen N=26</th>
</tr>
</thead>
<tbody>
<tr>
<td>C1a Problems understanding treatment aims</td>
<td>0.33</td>
<td>0.23</td>
<td>0.24</td>
</tr>
<tr>
<td>C1b Did doctors listen to concerns</td>
<td>0.00</td>
<td>0.41</td>
<td>0.36</td>
</tr>
<tr>
<td>C1c Enough info about condition</td>
<td>0.67</td>
<td>0.55</td>
<td>0.56</td>
</tr>
<tr>
<td>D19 Decisions made with input from relatives</td>
<td>0.00</td>
<td>0.48</td>
<td>0.42</td>
</tr>
<tr>
<td>D26a Enough info about dying process</td>
<td>0.67</td>
<td>0.83</td>
<td>0.81</td>
</tr>
<tr>
<td>D27a Enough info about action at time of death</td>
<td>0.67</td>
<td>0.74</td>
<td>0.73</td>
</tr>
<tr>
<td>D28a Enough info about medication for symptom control</td>
<td>0.33</td>
<td>0.65</td>
<td>0.62</td>
</tr>
<tr>
<td>E1 Kept informed with patient’s condition</td>
<td>0.67</td>
<td>0.57</td>
<td>0.58</td>
</tr>
<tr>
<td>Domain score (range 0 – 1)</td>
<td>0.42</td>
<td>0.56</td>
<td>0.54</td>
</tr>
</tbody>
</table>

Just over half (54%) of the family members, felt that care could be improved in this domain (42% of the Oncology group’s families and 56% of the General group’s families). This seems to be in line with the SUPPORT investigators who found that discussions about end-of-life issues were infrequent, and misconceptions of the patient’s preferences remained common, despite their vigorous attempts to improve the situation. (SUPPORT Principle Investigators, 1995) This is a very important domain of care for all patients, but
may be even more so in the care of the terminally ill patients and their families. It is interesting to note that 67% of the oncology relatives reported opportunity to improve in the field of information about the patient’s condition. Only three relatives were interviewed, which means that two of the three relatives felt this way. In the General group the highest problem scores were related to information about the death process (0.83), action at the time of death (0.74) and medication for symptom control (0.65). Of these relatives, only 23% thought treatment aims could be explained better.

### 3.2.5 Focus on individual

**Table 10. Focus on individual**

<table>
<thead>
<tr>
<th>Question</th>
<th>Onc n=3</th>
<th>Gen n=23</th>
<th>Onc+Gen n=26</th>
</tr>
</thead>
<tbody>
<tr>
<td>D21 Were patient’s personal needs addressed</td>
<td>0.33</td>
<td>0.48</td>
<td>0.46</td>
</tr>
<tr>
<td>D22 Patient treated with respect</td>
<td>0.33</td>
<td>0.30</td>
<td>0.31</td>
</tr>
<tr>
<td>D23 Treated with kindness</td>
<td>0.33</td>
<td>0.39</td>
<td>0.38</td>
</tr>
<tr>
<td>D24 Enough help with personal care</td>
<td>0.00</td>
<td>0.26</td>
<td>0.23</td>
</tr>
<tr>
<td>D25 Enough help with medication and dressings</td>
<td>0.00</td>
<td>0.13</td>
<td>0.12</td>
</tr>
<tr>
<td>E2 Concerns about personal needs of patient when absent</td>
<td>0.33</td>
<td>0.52</td>
<td>0.50</td>
</tr>
<tr>
<td>Domain score (range 0 – 1)</td>
<td>0.22</td>
<td>0.35</td>
<td>0.33</td>
</tr>
</tbody>
</table>

Focus on the individual and coordination of care is the two domains where Port Elizabeth private hospital patients seem to get the appropriate
attention. About 70% of all the families are satisfied that the care their relatives received with regard to these domains were appropriate. Questions relate mainly to appropriate, respectful and kind management of the patients. The Oncology group has a domain score of 0.22, indicating that 78% of the relatives were satisfied with the care. In the General group the areas that most needed to be improved, focused around the questions regarding personal care. Problem scores of 0.48 for the question "were needs addressed" and 0.52 for the question "did you have any concerns about personal needs when absent".

Respect for patient autonomy means that physicians must allow informed patients to determine what value they place on a chance of survival, what risks they are willing to undergo and respect the choice patients make. (Lo, 1995)

### 3.2.6 Provision of coordinated care

Table 11. Provision of coordinated care

<table>
<thead>
<tr>
<th>Question</th>
<th>Onc n=3</th>
<th>Gen n=23</th>
<th>Onc+Gen N=26</th>
</tr>
</thead>
<tbody>
<tr>
<td>C1d Confusing or contradictory info about treatment</td>
<td>0.33</td>
<td>0.50</td>
<td>0.48</td>
</tr>
<tr>
<td>C2 Always a doctor in charge</td>
<td>0.00</td>
<td>0.26</td>
<td>0.23</td>
</tr>
<tr>
<td>D15 Staff members give different opinions about pain treatment</td>
<td>0.50</td>
<td>0.38</td>
<td>0.39</td>
</tr>
<tr>
<td>D18 Not enough info available to medical personnel</td>
<td>0.00</td>
<td>0.17</td>
<td>0.15</td>
</tr>
<tr>
<td>Domain score (range 0 – 1)</td>
<td>0.21</td>
<td>0.33</td>
<td>0.31</td>
</tr>
</tbody>
</table>
Results indicate that this is one of the domains in care that seems to be best attended to. In both the Oncology and General groups, relatives indicated that the provision of coordinated care was good. Almost 80% of oncology families and almost 70% of general family members were satisfied with care their family members received. (Domain scores: oncology 0.21 and other wards 0.33).

In the Oncology ward \((n=3)\), one patient had no pain, one relative reported that the patient had received different opinions about pain treatment and one relative reported that the patient did not get different opinions about pain treatment. Hence the problem score of 0.50. There was always enough information available and a specific doctor in charge of these oncology patients. (Problem scores of 0.00 and 0.00) In the General ward the problem score for confusing or contradictory info about treatment is 0.50, indicating that 50% of relatives thought that this aspect of care could be improved. There hardly ever seemed to be a problem with insufficient information for medical personnel to give optimum treatment (Problem score 0.17).

3.2.7 Overall Rating Scales
In the rating scales category, participants were asked to rate the different domains on a rating scale, where ‘0’ meant the ‘worst’ possible care and ‘10’ meant the ‘best’ possible care. They were also asked to rate overall care on the same scale of ‘0’ to ‘10’. It was decided that scale scores of less than 6.5 could be regarded as areas that need attention. Scale score of 8 or more can be regarded as excellent care.
Table 12. Scale scores and their interpretation.

<table>
<thead>
<tr>
<th>Scale score</th>
<th>Interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td>8 or more</td>
<td>Excellent care</td>
</tr>
<tr>
<td>Between 6.5 and 8</td>
<td>Good care</td>
</tr>
<tr>
<td>Less than 6.5</td>
<td>Need attention</td>
</tr>
</tbody>
</table>

Table 13. Overall Rating Scales

<table>
<thead>
<tr>
<th>Question</th>
<th>Onc n=3</th>
<th>Gen n=23</th>
<th>Onc+Gen N=26</th>
</tr>
</thead>
<tbody>
<tr>
<td>F1 Communication (Range 1 – 10)</td>
<td>8.00</td>
<td>6.00</td>
<td>6.23</td>
</tr>
<tr>
<td>F2 Respecting wishes of patient</td>
<td>7.67</td>
<td>6.87</td>
<td>6.92</td>
</tr>
<tr>
<td>(Range 1 – 10)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F3 Symptom control</td>
<td>8.67</td>
<td>6.74</td>
<td>6.96</td>
</tr>
<tr>
<td>(Range 1 – 10)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F4 Ensuring that dignity was retained</td>
<td>8.33</td>
<td>7.10</td>
<td>7.27</td>
</tr>
<tr>
<td>(Range 1 – 10)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F5 Family care (Range 1 – 10)</td>
<td>7.67</td>
<td>6.04</td>
<td>6.23</td>
</tr>
<tr>
<td>F6 Overall care (Range 1 – 10)</td>
<td>9.00</td>
<td>7.69</td>
<td>7.85</td>
</tr>
<tr>
<td>Scale score average (Range 1 – 10)</td>
<td>8.22</td>
<td>6.74</td>
<td>6.91</td>
</tr>
</tbody>
</table>
The results indicate that relatives are generally satisfied with the care the patients received during their last few days in hospital. The Oncology team seems to be able to give a better service to their patients and relatives. In all the fields they rated care to be better than the General group (Scale score mean: Oncology 8.22 and General 6.74). Particularly high rates of satisfaction (all higher than 8 on a scale of 0 - 10) in the Oncology group were found in the fields of communication, symptom control, ensuring dignity and in the overall care (Scale scores of 8.00, 8.67, 8.33 and 9 respectively). In the General group the highest satisfaction rates were found in the fields of ensuring dignity and the overall care (Scale scores of 7.10 and 7.69 respectively).

Looking at these scale scores, it seems as though the vast majority of relatives are satisfied with the care their loved ones received in their last few days. The only areas with scores lower than 65%, was in the General group, were regarding the questions about communication and family care (Scale scores of 6.00 and 6.04).
### 3.2.8 Summary of results and discussion

Table 14. Comparison of all results

<table>
<thead>
<tr>
<th>Domain</th>
<th>Oncology n = 3</th>
<th>General n = 23</th>
<th>Oncology and General N = 26</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Range</td>
<td>Median</td>
<td>Domain score (M)</td>
</tr>
<tr>
<td>Physical/Emotional (5 items)</td>
<td>0.00- 0.67</td>
<td>0.50</td>
<td>0.43</td>
</tr>
<tr>
<td>Informing &amp; Decision Making (8 items)</td>
<td>0.00- 0.67</td>
<td>0.50</td>
<td>0.42</td>
</tr>
<tr>
<td>Advance Care Planning (3 items)</td>
<td>0.00- 0.33</td>
<td>0.33</td>
<td>0.22</td>
</tr>
<tr>
<td>Focus on Individual (6 items)</td>
<td>0.00- 0.33</td>
<td>0.33</td>
<td>0.22</td>
</tr>
<tr>
<td>Attend to Family (4 items)</td>
<td>0.33- 1.00</td>
<td>0.67</td>
<td>0.67</td>
</tr>
<tr>
<td>Coordination (4 items)</td>
<td>0.00- 0.50</td>
<td>0.33</td>
<td>0.21</td>
</tr>
</tbody>
</table>
From the above it is clear that the assessed domain that constantly showed most opportunity for improvement is the domain of ‘attending to the needs of the family members’. In the oncology group, 67% of family members thought care could improve, while 85% of family members in the general group indicated that care could be improved.

It is interesting to note that the next highest domain score, indicating opportunity for improvement in the General group, namely encouragement of advanced care planning, (Domain score of 0.61, range 0.43 – 0.80, median 0.76), was actually one of the lowest scoring domains in the Oncology group (Domain score of 0.22, range 0.00 – 0.33, median 0.33).

The domains that needed the least improvements in both the General and the oncology groups are focus on the individual (Domain score oncology 0.22, range 0.00 – 0.33 and median 0.33. Domain score general 0.35, range 0.13 and median 0.34) and coordination of care (Domain score oncology 0.22, range 0.00 – 0.50 and median 0.33. Domain score general 0.35, range 0.17 – 0.50 and median 0.32).

In general, the Oncology team seems to have less opportunity to improve in all the various domains. The Oncology group in general, is seemingly orientated towards better end-of-life care as many of their patients are suffering from incurable diseases. This is as opposed to the General group where cure and optimal function is the main aim. The local Oncology team does have a social worker who is working as a counsellor and that might be part of the
reason why they seem to do better in some of the domains. The results for the domains of coordination of care, which focuses on the individual patient and advanced care planning, indicate that the family members regard these domains as having little opportunity for improvement. Almost 80% of families indicated that they were satisfied with care in these areas. According to Morita, Chihara & Kashiwagi (2002) the presence of attending social workers considerably enhances the caregiver satisfaction in situations of terminal care.

In the domains of physical and emotional care of the patient and information and decision-making, almost 60% of the Oncology families were satisfied with the care received. Although scores are more positive than for the General group, they do reveal that relatives indicated that the service could still be improved.

'The SUPPORT data presented a challenge to physicians. It would be simple if computers and nurses alone could improve the care of the seriously ill patients. Instead, physicians will need to change hospital culture and practices and our own behaviour. These are daunting tasks particularly at a time when many physicians complain that managed care is undermining professional autonomy and reducing us to pawns in impersonal organisations. Although our resources may be restricted, nonetheless, we need to reaffirm our traditional responsibility for relieving pain, responding to our patients' concerns, helping them make difficult decisions and respecting their informed choices'. (Lo, 1995)

3.4 Limitations

It must be kept in mind that this was a very small study. Of the forty-eight adults who died in April 2002, thirteen were excluded. Thirty-five patients died expected, natural deaths in private hospitals in this period. Four family members refused participation in the study and the other five family members could not be located for interviews. These families who could not be contacted or refused could have strong views, either positive or negative, with regard to
care and this may have influenced the results if they had been included. Families of only three oncology patients and twenty-three other patients were interviewed.

This study did not investigate family members' expectations, personalities, adaptation to dealing with a situation with a terminal illness and cultural background. Family members' views may change with the process of bereavement and are influenced by their own feelings (anger, bitterness, sadness, frustrations, etc.). Their reports will also depend on the extent to which the patients shared their own feelings with the family members. However, the question is not whether the family member's report accurately reproduces the patient's response, but that they are able to identify important opportunities to improve and enhance the care of the dying patient.

3.3 CONCLUSIONS

As a descriptive study with limited numbers this study cannot make any conclusive claims with regard to the care that terminal patients receive in private hospitals in Port Elizabeth. Although the views of bereaved family members are far from optimal this research does give some insight into the care these patients received in their last few days. It is interesting both from the point of view of understanding what went right and what went wrong and highlighting potential areas with opportunity to improve.

Results indicate that the single domain with most opportunity to improve for both the oncology group and the general group is attention to the family. The model patient-focused family-centred care, which is applicable to palliative care, makes this an urgent opportunity for improvement. Control of pain and other symptoms remain an important medical and ethical issue. Pain is but the tip of the iceberg when it comes to symptom control. Although patients suffer for many reasons, physicians can contribute substantially to the prevention or relief of suffering by controlling pain.
The fact that domains with the least improvement opportunities, namely the focus on the individual and the coordination of the care, makes sense if it is kept in mind that the research was done in private hospitals. It can be accepted that doctors and other staff would go out of their way to accommodate individual patients and that they would strive to optimally coordinate the care. It would be interesting to compare these areas in particular with public hospitals and our local hospice where there are no specific financial incentives. (As opposed to private hospitals.) The patients, who die in private hospitals, are considered to be the privileged few in a society where the vast majority of people are in the position of having to cope with only the public facilities available to them.

High quality of care is a result or outcome of care, but it’s more about what the staff do, and how they deliver services. How and what services are delivered, such as communication, information giving and practical support, have a major effect on quality of life, often as much as symptom control.

This investigation indicated that families are not in general unhappy about the care dying patients in private hospitals in Port Elizabeth received, but that there are unmet needs and that there is room for improvement in their care.
4 SUMMARY AND RECOMMENDATIONS

As a descriptive study with limited numbers this study cannot make any conclusive claims with regard to the care that all terminal patients receive in private hospitals in Port Elizabeth. Results indicate that the single domain with most opportunity to improve for both the oncology group and the general group is attention to the family. The model of patient-focused family-centred care, which is applicable to palliative care, makes this an urgent opportunity for improvement in the care of the dying patients in private hospitals. Control of pain and other symptoms remains an important medical and ethical issue, indicated in this research as needing attention. Information and promotion of shared decision-making is the other domain that warrants attention. The fact that domains with the least improvement opportunities are the focus on the individual and the coordination of the care makes sense if it is kept in mind that the research was done in private hospitals.

This investigation indicated that families are not in general unhappy about the care dying patients in private hospitals in Port Elizabeth received. Dying patients and their families, however, do have needs that are not currently being acknowledged and adequately met by the way they are managed in private hospitals. There is a definite need for palliative care in private hospitals, but the challenge is to get the medical fraternity to acknowledge that and accept palliative care as a much-needed service in private sector medicine. Practicalities of establishing palliative care in private practice in Port Elizabeth and in South Africa will make interesting material for future studies.

Dying can be seen as an inevitable stage of human life, which holds the potential for suffering as well as important opportunities for personal growth. It
is a time when medical care should be patient focussed and family centred. Patients who are dying may find some quality of in life, even when their quality of life as assessed by current measures is abysmal. (Farsides & Dunlop, 2001) Medical literature seems to grow exponentially with evidence of inadequate medical care at the end of life. Too often, medical prognosis and goals of care are not discussed, symptoms such as pain are under assessed and under treated and psychosocial or spiritual issues are ignored. (Meyer, 2000)

If we look at developed countries with first world opportunities and years of experience in the field, we have to admit that we still have a long, long battle to fight. Cassel & Meier (2001) stated that current barriers to providing adequate palliative care in the United States include the following: financing mechanisms, lack of adequate supply of trained physicians, lack of continuity of care, cultural issues (seeing death as a failure, discomfort about talking about death) and physician attitudes (as part of the culture described above.) Yes, in South Africa we are challenged indeed!

Palliative care consultation services and specialty units are a response to the shortcomings of the curative health model for patients for whom no cure exists. (Von Gunten, 2002) A complete mind shift will be needed here to get the medical fraternity to accept palliative care something that is needed and that it can trusted to help to take care of those patients with a limited life expectancy.

4.1 RECOMMENDATIONS

In establishing a palliative care inter professional programme, working from the existing oncology unit as base, could be the initial point of focus. The oncologists are in a position where their patients frequently have a limited life expectancy. They are often sensitised to the many needs of their own patients and their loved ones. In a busy daily schedule, it might not always be possible
to commit their time to the time consuming consultations and family conferences.

Working from there would have the advantage that patients do not have to go 'somewhere else' to be seen, if 'nothing else' can be done any more in a curative sense of the word. This kind of 'transfer of ownership' of the patient, be it temporary (till he has to go back to the oncology team for irradiation for new bony metastases, for example) or permanently (till they die) can be devastating for both the patient and the family members. They may feel, and not unjustifiably so, abandoned by the system that took care of them from the time they were diagnosed. Being referred to a palliative team could be as easy as an appointment next-door with the palliative doctor or nursing sister, similar to that of an appointment with the social worker, physiotherapist, dietician, and psychologist. The aim would be to provide a continuum of care and follow-up or in some cases death and bereavement, ensuring the best possible best quality of life.

Practitioners from all medical fields could refer patients to the palliative care team and if patients can be helped with palliative care input whilst they are still in a hospital, their original doctors could visit and observe the effects of the palliative interventions. This is as opposed to referring patients away to hospice or oncology ward and loosing contact with the patient. The idea behind this initial plan is to convince physicians of the value of the palliative care team. Obviously, once the principle is accepted, and a palliative care team is established, the team could work much wider, in all hospitals, frail care units, step down facilities and at the homes of individual patients.

Palliative care requires time consuming consultations, often on a regular basis, for both the patient and the family. The reason for that being the emotional, psychosocial, existential issues that are added to the physical challenges that these patients present with Even in the United States the 'relief of suffering' as a legitimate goal of admission is not specifically recognised.
(Cassel & Meier, 2001) At the moment we do not have special codes to claim from medical aids for palliative care interventions. This will have to be addressed at the appropriate level to make palliative medicine a financially viable option in private practice.

Lynn (2000) has an interesting opinion on the future of palliative medicine: ‘Research, education, quality improvement and advocacy concerning the end of life arise largely from the shared discomfort with current shortcomings in care and the growing vision of better ways to serve those who are very sick. Thus, the field demands reform and reformers. The clinical work is humbling, meaningful, community based and collaborative in nature. Perhaps the field will evolve with uniquely collaborative approaches across professions and programs and also with more attention to community resources and culture, public health methods and frameworks, and spiritual and familial relationships. Deep understanding and rapid change are urgently needed. Today unnecessary suffering is a strong motivation for rapid improvement.’ ‘How people die, remains in the memories of those who live on’ the founder of the hospice movement, Dame Cecile Saunders said. (1989)

4.2 SUGGESTIONS FOR FUTURE STUDIES

From the current study it is clear that, although family members are in general satisfied with care of dying patients in our private hospitals, there is indeed opportunity for improvement in the management of this specific group of patients. It is indicated that initiative could be taken in practising palliative medicine independently from hospice in Port Elizabeth.

Future research could focus on the practical and financial viability of such a development and comment on the implementation of the plan and the initial
stages of development. Improving the experience of the dying will undoubtedly require several simultaneous reforms. Portenoy (2001) suggests creating a business plan to ‘mainstream’ palliative medicine. Doing this in our South African private medicine situation, will be ground breaking work in South Africa.
5 BIBLIOGRAPHY


at the End-of-Life through Fast-tracking audit, standards, and teamwork (EXCELFAST). *Journal of Pain and Symptom Management* 17: 75-82.


6 APPENDICES

6.1 APPENDIX 1: LETTER TO PHYSICIANS

(Printed on a hospital letterhead and posted to physicians.)

Dear Dr ‘ABC’

The hospital management has given Dr G van Heerden approval to do her research in ‘AA’ HOSPITAL. It is a project intended to promote the best quality of care for seriously ill patients and their family members. She is a medical doctor currently doing her M (Phil) in Palliative Medicine through the University of Cape Town. The research she is doing for her thesis is structured around the 'Unmet needs of dying patients in private hospitals'. The specific aim is to review the overall care of patients who died of expected, natural causes during the month of April in 2002. We are doing this by speaking with bereaved family members telephonically, who can provide important information about a loved one’s medical care at the end of life. We would like to learn about their perspective on the patient's experience at the hospital and their own experience during that time. A questionnaire from the Brown University, Massachusetts will be used.

In the death register of the hospital, your name was linked to Mr ‘XYZ’ who died on the ‘X’ th of April. If his death was not an expected, natural death, the patient should be excluded from the study. If, for any reason, you would prefer the family members not to be contacted for this interview, please let us know by phoning me at ‘041 111 222 333’.

All information will be held in strictest confidence and no patient; family member or doctor will be identified in any reports that result from this project. If you would like to have a look at the research proposal and/or the questionnaire, a copy will be delivered to your rooms. If you need more
information on this project, you are welcome to contact Dr van Heerden (at 0822 024 078 or e-mail: ceegee@intekom.co.za) or myself.

We are confident that this project will enable us to continue to promote the highest-level quality of care for seriously ill patients and their family members. With this goal in mind, we very much hope that you will not object to these people being interviewed.

Sincerely,

Mrs ‘B ABC’

(041 111 222 333)

pp Mr ‘MNO’, Hospital Manager, ‘AA’ Hospital.

Ps. Palliative medicine is the care of patients with active, progressive, far-advanced disease and a short life expectancy, for whom the focus of care is the relief and prevention of suffering and the best possible quality of life. The goals are to provide relief from pain and other physical symptoms, to maximize the quality of life whilst neither hastening nor postponing death, to provide psychosocial and spiritual care and to provide support to help the family during the patient’s illness and bereavement.
6.2 LETTER OF INTRODUCTION TO BEREAVED FAMILY MEMBERS:

(Printed on a hospital letterhead and posted to family members)

Dear Mrs. ‘XYZ’,

I am writing on behalf of (St Georges/ Mercantile/ Greenacres) Hospital and the University of Cape Town. We are saddened by the loss of [patient’s name] and hope that you have been doing as well as possible during this difficult time.

Currently, we are working on a project intended to promote the best quality of care for seriously ill patients and their family members. We are doing this by speaking with people, such as you, who can provide important information about a loved one’s medical care at the end of life. We would like to learn about your perspective on the experience of [patient’s name] at our hospital and your own experience during that time.

Specifically, we are asking you to participate in this project by agreeing to be interviewed over the telephone. If you decide to agree to an interview, everything that you tell us will be held in strictest confidence. We will not identify you or [patient’s name] in any reports that result from this project.

If you prefer not to participate in this project, you can call me at 041 111 222 333 to notify us of your wishes before May the 20th. Upon receiving a call from you indicating that you do not want to participate in this study at this time, no one from the study team will contact you again about this project.

If we do not hear from you before the 20th of May, Dr G van Heerden, who is doing the project, will phone you to make an appointment to phone you at a convenient time for the interview.

We are confident that this project will enable us to continue to promote the highest-level quality of care for seriously ill patients and their family
members. With this goal in mind, we very much hope that you will agree to participate in a telephone interview. We look forward to talking with you.

Sincerely,

Mrs ‘B ABC’

(041 111 222 333)

Pp Mr ‘MNO’, Hospital Manager, ‘AA’ Hospital.
6.3 APPENDIX 3: TELEPHONIC CONSENT

To be read by discussed with the person being interviewed at the start of the telephonic conversation. This person would have received the introductory letter.

'To make sure you have all the information about the study, I am going to read you a few sentences. Your participation in this interview is, of course, voluntary. If you decide not to participate, it will not affect you in any way.

Your answers will be kept completely confidential to the extent of the law. The information from this study will not be presented or published in any way that would allow the identification of any respondent; patient or doctor. Your answers will be combined with the answers of other people for statistical analysis.

It is important that your answers be accurate. Take your time and be sure to ask me if you are not sure what a question means or what kind of answer is wanted. It is very important that you answer as honestly and as accurately as you can. If there is any question you would rather not to answer, just tell me and I will skip it.

Do you have any questions about the study? May we proceed with the interview?'

If 'yes', continue the interview.

If 'no', thank respondent and terminate interview.
APPENDIX 4: QUESTIONNAIRE

i) Physical comfort and emotional support:

D12. During his/her last few days, was [PATIENT] on medicines to treat (his/her) pain?

[ ] YES

[ ] NO (SKIP TO D15)

[ ] DON'T KNOW (SKIP TO D15)

D12a. During his/her last few days, did (his/her) doctor or the medical staff who cared for (him/her) tell you about how (his/her) pain would be treated, in a way that you could understand?

[ ] YES

[ ] NO

D15. During his/her last few days, did [PATIENT] receive too much, too little, or just the right amount of medication for (his/her) pain?

[ ] TOO MUCH

[ ] TOO LITTLE

[ ] RIGHT AMOUNT
D15a. During his/her last few days, was there ever a time when one doctor or nurse said one thing about treatment of (his/her) pain and another said something else?

[ ] YES

[ ] NO

16. During his/her last few days, did (he/she) have trouble breathing?

[ ] YES

[ ] NO (SKIP TO D17)

[ ] DON'T KNOW (SKIP TO D17)

16b. How much help in dealing with (his/her) breathing did [PATIENT] receive - less than was needed, or about the right amount?

[ ] LESS THAN WAS NEEDED

[ ] RIGHT AMOUNT

D17. During his/her last few days, (did (he/she) have any feelings of anxiety or sadness?

[ ] YES

[ ] NO (SKIP TO D18)

[ ] DON'T KNOW (SKIP TO D18)
D17b. How much help in dealing with these feelings did [PATIENT] receive—less than was needed or about the right amount?

[ ] LESS THAN WAS NEEDED

[ ] RIGHT AMOUNT

ii) Information and promotion of shared decision-making:

C1. During his/her last few days, did you talk with any of [PATIENT’S] doctors yourself?

[ ] YES

[ ] NO

C1a. During his/her last few days, was there ever a problem understanding what any doctor was saying to you about what to expect from treatment?

[ ] YES

[ ] NO

C1b. During his/her last few days, did you feel that the doctors you talked to listened to your concerns about [PATIENT’S] medical treatment?

[ ] YES

[ ] NO

[ ] HAD NO CONCERNS
C1c. During his/her last few days, how much information did the doctors provide you about [PATIENT’S] medical condition - would you say less information than was needed, just the right amount, or more than was needed?

[ ] LESS THAN WAS NEEDED

[ ] JUST THE RIGHT AMOUNT

[ ] MORE THAN WAS NEEDED

D19. During his/her last few days was there ever a decision made about (his/her) care without enough input from (him/her) or (his/her) family?

[ ] YES

[ ] NO

D26. At any time while [PATIENT] was in the hospital did you or your family receive any information about what to expect while (he/she) was dying?

[ ] YES

[ ] NO

D26a. Would you have wanted (some/more) information about that?

[ ] YES

[ ] NO
D27. At any time while [PATIENT] was in the hospital did you or your family receive any information about what to do at the time of (his/her) death?

[ ] YES
[ ] NO

D27a. Would you have wanted (some/more) information about that?

[ ] YES
[ ] NO

D28. At any time while [PATIENT] was in the hospital did you or your family receive any information about the medicines that would be used to manage (his/her) pain, shortness of breath, or other symptoms?

[ ] YES
[ ] NO

D28a. Would you have wanted (some/more) information about the medicines?

[ ] YES
[ ] NO

E1. During his/her last few days, how often were you or other family members kept informed about [PATIENT’S] condition – always, usually, sometimes, or never?
[ ] ALWAYS

[ ] USUALLY

[ ] SOMETIMES

[ ] NEVER

iii) Encouragement of advanced care planning:

D1. Did [PATIENT] have specific wishes or plans about the types of medical treatment (he/she) did or did not want while dying?

[ ] YES

[ ] NO (SKIP TO D5)

[ ] DON'T KNOW (SKIP TO D5)

D2. To the best of your knowledge, did [PATIENT]'s doctor or the medical staff who cared for (him/her) while under care of the hospital speak to (him/her) or you about (his/her) wishes about medical treatment?

[ ] YES

[ ] NO

D3. Did (his/her) doctor or the medical staff who cared for (him/her) while under care of the hospital speak to (him/her) or you about making sure (his/her) care was consistent with (his/her) wishes?

[ ] YES
D4. During his/her last few days, was there any medical procedure or treatment that happened to (him/her) that was inconsistent with (his/her) previously stated wishes?

[ ] YES

[ ] NO

iv) Focus on the individual:

D21. During his/her last few days, how often were [PATIENT'S] personal care needs - such as bathing, dressing, and changing bedding - taken care of as well as they should have been - would you say always, usually, sometimes, or never?

[ ] ALWAYS

[ ] USUALLY

[ ] SOMETIMES

[ ] NEVER

D22. During his/her last few days, how often was (he/she) treated with respect by those who were taking care of (him/her) - always, usually, sometimes, or never?

[ ] ALWAYS

[ ] USUALLY
D23. During his/her last few days, how often was [PATIENT] treated with kindness by those who were taking care of (him/her) – always, usually, sometimes, or never?

[ ] ALWAYS

[ ] USUALLY

[ ] SOMETIME

[ ] NEVER

D24. During his/her last few days was there enough help available to meet (his/her) personal care needs, like bathing, dressing, feeding, and going to the bathroom?

[ ] YES

[ ] NO

D25. During his/her last few days was there enough help with medications and getting dressings changed?

[ ] YES

[ ] NO
E2. While [PATIENT] was under care of the hospital, how often did you have concerns about [PATIENT’S] personal care needs – such as bathing, dressing, and changing bedding- being met when you were not there - always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

v) Attendance to the emotional and spiritual needs of the family:

E4. While [PATIENT] was under care of the hospital, did someone talk with you about your religious or spiritual beliefs?

[ ] YES
[ ] NO (SKIP TO E6)

E4a. Was this done in a sensitive manner?

[ ] YES
[ ] NO

E4b. Did you have as much contact of that kind as you wanted (in [PATIENT’S] last week/ while [PATIENT] was under care of hospital)?

[ ] YES
E6. During his/her last few days how much support in dealing with your feelings about [PATIENT'S] death did the doctors, nurses, and other professional staff taking care of (him/her) provide you - less support than was needed or about the right amount?

[ ] LESS THAN WAS NEEDED

[ ] RIGHT AMOUNT

E7. During his/her last few days, did a doctor, nurse, or other professional staff taking care of [PATIENT] talk about how you might feel after [PATIENT'S] death?

[ ] YES → Was it done in a sensitive manner?

[ ] YES [ ] NO

[ ] NO → Would you have wanted them to?

[ ] YES [ ] NO

E8. (In [PATIENT'S] last week/ While [PATIENT] was under care of the hospital), did a doctor, nurse, or other professional staff taking care of [PATIENT] suggest someone you could turn to for help if you were feeling stressed?
[ ] YES
[ ] NO

vi) Provision of coordinated care:

C1d. (In that last week/While under care of the hospital), how often did any doctor give confusing or contradictory information about [PATIENT'S] medical treatment - always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

C2. (In that last week/While under care of the hospital), was there always a doctor in charge of [PATIENT]'s care?

[ ] YES
[ ] NO

C2a. (In that last week/While under care of the hospital), was it always clear to you which doctor was in charge of (his/her) care?

[ ] YES
[ ] NO
D15a. (In that last week/ While under care of the hospital), was there ever a
time when one doctor or nurse said one thing about treatment of (his/her)
pain and another said something else?

[ ] YES

[ ] NO

D18. (In that last week/ While under care of the hospital), was there any
problem with doctors or nurses not knowing enough about [PATIENT'S]
medical history to provide the best possible care?

[ ] YES

[ ] NO

vii) Overall rating scales for patient focused, family centred care:

Ratings: Now we would like you to rate some aspects of the care [patient]
received (in that last week/ while (he/she) was under care of the hospital). For
each of the following questions, I'm going to ask you to use a scale from 0 to
10, where 0 means the worst care possible and 10 means the best care
possible.

F1. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of
the hospital), how well did the doctors, nurses, and other professional staff who
cared for [PATIENT] communicate with (him/her) and the family about the
illness and the likely outcomes of care?

[0 1 2 3 4 5 6 7 8 9 10]
F2. (In the last week of [PATIENT’S] life/ While [PATIENT] was under care of the hospital), how would you rate how well those taking care of [PATIENT] provided medical care that respected (his/her) wishes?

[0 1 2 3 4 5 6 7 8 9 10]

F3. (In the last week of [PATIENT’S] life/ While [PATIENT] was under care of the hospital), how well did those taking care of [PATIENT] make sure (his/her) symptoms were controlled to a degree that was acceptable to (him/her)?

[0 1 2 3 4 5 6 7 8 9 10]

F4. (In the last week of [PATIENT’S] life/ While [PATIENT] was under care of the hospital), how well did those taking care of [PATIENT] make sure that [PATIENT] died with dignity - that is, died on (his/her) own terms?

[0 1 2 3 4 5 6 7 8 9 10]

F5. (In the last week of [PATIENT’S] life/ While [PATIENT] was under care of the hospital), how well did those taking care of [PATIENT] do at providing emotional support for you and [PATIENT’S] family and friends?

[0 1 2 3 4 5 6 7 8 9 10]

F6. On a scale of 0 to 10, where 0 means the worst care possible and 10 means the best care possible, what number would you give the overall care that [PATIENT] received in [PATIENT’S] last week of life/ while [PATIENT] was under care of the hospital)?

[0 1 2 3 4 5 6 7 8 9 10]