

**AN AUDIT OF REFERRING PATTERNS FOR CANCER PATIENTS  
TO THE PALLIATIVE CARE UNIT IN 2 MILITARY HOSPITAL,  
BY MEANS OF A RETROSPECTIVE EVALUATION OF THE  
PERCENTAGE OF REFERRALS ADHERING TO A GIVEN  
STANDARD, AND EVALUATION OF POSSIBLE BARRIERS.**

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I, Maria Johanna Engelbrecht declare that this Audit is my own work. It is part of the requirement for the M Phil. Palliative Care degree from the University of Cape Town, South Africa. It has not been submitted for any degree or examination at this or any other University before.

Signed by candidate

I dedicate this work to  
Mariëtta Van Den Berg, who introduced me to this  
medical field and made my working experience an  
absolute joy.

## ABSTRACT

### **Introduction**

The 2 Military Hospital Palliative Care unit seeks to provide high quality, holistic palliative care to all patients suffering from life-threatening diseases. This care should be initiated early after the diagnosis, to prevent unnecessary suffering and allowing the patient and the family to be part of the decision making process.

However, the majority of the cancer patients are either referred very late in the disease process or not referred at all. The purpose of this study was to enumerate the percentage of patients diagnosed with cancer who were not referred to the palliative care unit; to identify possible barriers to referral within referring doctors and to promote the role of the palliative care unit. The study was done in the form of an audit cycle of which a standard was set at 80% of cancer patients to be referred to the PCU within 14 days of diagnosis.

### **Methods**

Our current practise was evaluated by means of a retrospective study of referrals to our PCU over a 6 month period. A referral rate was calculated and the time lapse between the diagnosis and referral was recorded. These results were used as a discussion point with the different heads of department.

From the discussions, barriers to referral were identified; changes were implemented and practise was reviewed after 3 months.

## **Results**

The percentage of patients with newly diagnosed cancer referred to the PCU before intervention was 57,5% In the discussions with the heads of departments four categories of barriers were identified - within the patient, within the referring doctor; in the system and the type of cancer.

The main reason for non -referral seemed to be the lack of awareness of the PCU's functions. After intervention 84,6% of cancer patients were referred by means of referral letters, However only 30,7% of the patients were referred and seen by the PCU within 14 days after the diagnosis.

## **Conclusion**

Intervention resulted in an increased number of patients being referred, However patients were not attending the unit due to the late timing of the referrals. Patients were referred at discharge rather than during their hospital stay. This resulted on patients not being seen by the PCU.

Communication between the departments has been poor and doctors experience an number of barriers to referral which need to be addressed. In particular a paradigm shift is needed to emphasize shared care and team work between departments for patients with cancer

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University of Cape Town

## INTRODUCTION

2 Military Hospital is one of three military hospitals in the country. It provides a medical service to all National Defence Force members of the Western Cape.

This includes all current serving military members, their dependants as well as retired members and their dependants.

A palliative care unit was established in the hospital 6 years ago and functions as a ward within the hospital. It consists of four single rooms for terminal patients and two six-bed rooms for pre-terminal or rehabilitating patients.

The unit uses a holistic approach to the care of patients. The focus is on the spiritual and emotional aspects of pain, as well as physical needs. Family meetings are used for identifying goals of care as well as sharing information. An interdisciplinary team consisting of medical doctors, nursing staff, a social worker, physiotherapist, occupational therapist, speech therapist, psychologist and religious leaders work together to provide an integrated approach to management.

The functions of the unit are:

- Care of dying patients and support for their families, which includes counselling.
- Symptom control of cancer patients
- Liaison between cancer patients and oncology units. [The Military Hospital does not have an oncology unit and patients have to be referred to outside units. This includes patients who have a “curable” disease.]

- Administration of treatment authorities.
- Keeping of a cancer registry for annual updating of the national cancer registry.
- Identification and treatment of side effects of cancer treatments such as chemotherapy and radiotherapy.
- Rehabilitation of patients who have had amputations or developed spinal cord lesions as part of the cancer disease process.

The problem is that patients are often referred to the palliative care unit at a very advanced stage of illness. This results in patients not receiving the care and support they need and they often present at the hospital with problems, which could have been prevented e.g. severe uncontrolled pain, vomiting, dehydration and constipation. This severely compromises the patient's quality of life.

The aim of this project is to maximise the referral of patients diagnosed with cancer to the palliative care unit at the Military Hospital, in order that they might receive optimal care.

#### Specific objectives

1. To enumerate the percentage of patients diagnosed with cancer who are not referred to the palliative care unit at 2 Military Hospital
2. To identify reasons why patients are not referred to the Palliative Care Unit.
3. To promote the role and function of Palliative Care Units

## LITERATURE REVIEW

### Medical Audit

Medical audit has been described as:

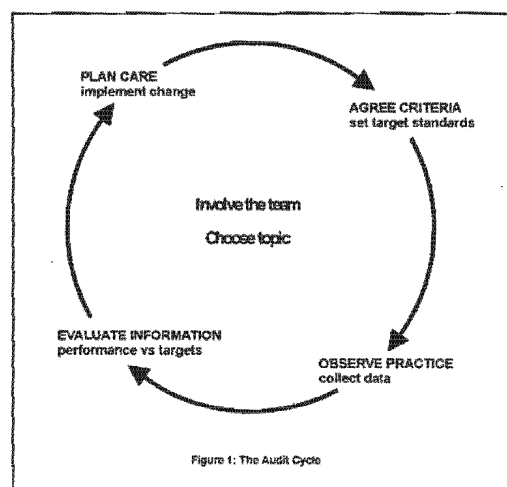
*“the attempt to improve the quality of medical care by measuring the performance of those providing that care, by considering the performance in relation to desired standards, and by improving on this performance.”<sup>1</sup>*

Although the term may sound uncharacteristic for the medical profession it was initially adopted to review the outcome of medical care rather than assessing and improving the quality of the medical service.

Four dimensions of quality were identified by Black – effectiveness, equity, humanity and efficiency. These emphasise the medical perspective concerned with clinical effectiveness, the patients’ views on care and the society’s perspective concerning costs. Medical performance was described in terms of quality that had to be assessed, improved and finally had to be assured to be maintained.

A medical audit can be viewed as a cycle, consisting of assessment and improvement of the quality of the topic being considered. Only by completion of the cycle can the quality be assured.

The elements of the cycle are involving the team; agreeing on criteria and levels of performance; observing practise and collecting data; evaluating information; planning care and implementing change; and repeating the cycle. <sup>1</sup>



## **Palliative care**

Palliative care grew out of the hospice care movement, a special system of comprehensive care for the dying.

Palliative care is defined by the World Health Organisation as:

*“The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is the achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anticancer treatment.”* <sup>2</sup>

Although the definition may initially imply that it is an alternative to life-prolonging care, it goes on to include palliative care in conjunction with curative care. All life-threatening disease may benefit from the palliative approach.

The key elements for helping the patient and the family live optimally during a life-threatening illness includes the assurance of physical comfort, providing psychosocial and spiritual support and providing co-ordinated services across various sites of care.<sup>3</sup>

Palliative care originally referred to patients with terminal disease, but now can be considered appropriate for all patients with chronic progressive life-threatening disease.<sup>4</sup>

The Last Acts Campaign's Task Force adopted a second definition:

*"Palliative care refers to the comprehensive management of physical, social, spiritual and existential needs of patients, particularly those with incurable, progressive illnesses. Palliative care affirms life and regards dying as a natural process that is a profoundly personal experience for the individual and the family. The goal of palliative care is to achieve the best quality of life through the relief of suffering, control of symptoms and the restoration of functional capacity while remaining sensitive to personal, cultural, and religious values, beliefs, and practises"*<sup>4</sup>

As the goals of palliative care are among the central purpose of the medical profession it needs to become part of primary medical care so that the division between medical care of patients who are perceived as having curable or chronic disease and those who are perceived as dying become a continuum with the palliative measures gradually taking precedence over life-prolonging efforts when death is imminent.<sup>3</sup>

Additionally, as transition from traditional curative care to palliative care can be difficult for both the patient and the health care professional<sup>3</sup> and because it is not possible to predict timing of death accurately and consistently, palliative care interventions should be incorporated early in the patient's course of illness.<sup>3</sup>

Palliative care/Hospice strives for more than pain relief or physical comfort during the last phase of life. It is a comprehensive program that includes care of the psychosocial and spiritual needs of the patient and those close to the patient. The goal is to help provide a period of relative comfort at the end of life, allowing for growth and closure for patients. This requires time and patience. Usually preparation for death takes months and cannot be accomplished in a few days.<sup>5</sup>

Palliative care openly acknowledges dying and does not always consider death a failure of the medical profession. It is not characterised by less care or withdrawal of care. It may even require intensive and sophisticated medical interventions to improve the quality of life or relieve suffering.<sup>3</sup>

### **Advantages of Palliative Care**

In a study done by the Edmonton Regional Palliative care Program in Canada, it was found that denied access to a palliative care unit resulted in patients dying in acute care facilities after medium to long-term stays. On the other hand increased access to palliative care and improved planning of care have resulted in a decrease in total inpatient

bed use. Thus cutting costs and making use of resources more effectively as the personnel in the palliative care institutions were trained in the management of physical and psychological complications of terminal care<sup>6</sup>

### **Disadvantages of Palliative Care**

The main disadvantage when a full time palliative care specialist or unit delivers care, is that it does not promote education on palliative care delivery among general physicians. This results in fostering dependency and reducing the likelihood of physicians applying knowledge earlier in the course of illness or to patients with diseases other than cancer. In addition the patients and their families are forced to establish a new relationship with a different treating doctor, and they may delay and decrease the rate of referrals by the primary physician or specialist who want to remain the treating physician.<sup>6</sup>

### **Why then palliative care?**

It could be said that all medical professionals should be involved in palliative care, the specialists, the family physicians and the oncologists. So, is there a case for palliative care specialists and/or units?

The symptoms of incurable disease appear and advance with speed, with variation in different tumours and individuals. Family support may start to disintegrate, buried personal and spiritual issues may emerge, and complex medico-social and psychological problems may occur, that cannot be postponed until the next clinic appointment. These

problems need time, patience and skill for resolution. Specialists and oncologists might not be able to provide the necessary intensity of support during the terminal phase.

Towards the end frequent clinical assessment is essential and short appointments in a follow-up clinic are imperfect instruments with which to provide the range of therapies necessary for these patients. Such factors justify the emerging category of palliative care physicians and units.<sup>7</sup>

### **Reasons for late or non-referral**

Hospice seeks to provide high quality, holistic end-of-life care, but unfortunately a majority of patients are not referred to the hospice until they are very close to death.

Palliative/Hospice care for patients and their families are a relatively new concept worldwide. It was perceived as an anti-establishment movement in the USA, because hospice care focuses on care at a time when cure or prolongation of life is not medically possible or desired. The development of this perceived diversion between “alternative hospice care” and standard medical care has presented a significant barrier to appropriate and timely referral of patients for hospice care.<sup>8</sup>

In a survey by Von Gunten, Von Roenn, Neely, Martinez and Weitzman, physicians were asked what they thought prevented physicians from referring patients to a palliative care unit or hospice

Their responses included the following:

- lack of understanding and/or knowledge about hospice
- difficulty in presenting death and dying issues to patients
- patient and family resistance to referral
- not understanding eligibility criteria
- feelings of “failing” or “giving up”
- concerns about hospice staff not acknowledging the expertise of the referring physicians
- a fear of patients being over medicated

The reasons preventing referral appears to be lack of familiarity, understanding and/or misperceptions about hospice care. This suggests that if these were addressed, overall referrals should improve. <sup>8</sup>

In another study by Farnon and Hofman <sup>5</sup> it was suggested that physicians and specialists tend to hold on to cure-orientated care until death was very close. They identified three characteristics:

- Cultural values, beliefs and experiences have important influences on end-of-life decisions. There is still a historical distrust of African Americans towards the medical establishment, where racism remains a problem. The authors quoted Neubauer who found that the African American group wanted to live as long as possible under almost any circumstances. He noted that hospice care might be

interpreted as giving up in the midst of adversity and that the humanitarian motives of predominantly white hospice workers might be doubted.

- Enrolment of patients with non-cancer diagnosis is difficult. In the USA hospice medical benefits are only applicable if a patient's life expectancy is six months or less. Prognostication of time of death is much more difficult with non-cancer patients
- Specialists tend not to relinquish a curative approach for a palliative approach until death is very close. Physicians are the gatekeepers to hospice referral but very few have formal training in palliative care and most do not know how to transfer their patients to a hospice program.

In a study by Pugh,<sup>9</sup> differences in the perceptions and characteristic of GP's were investigated. Doctors were divided into two groups, those referring frequently and those not referring at all.

In both groups the main reason for not referring was that the GP's felt that the carers were coping well without intervention. Both groups also felt that continuity of care was another valid reason for not referring. GP's felt that they did not want to break the trust and friendship that developed over a period of time.

It is generally believed that patients requiring palliative care will increase in future, due to the increased number of elderly people and a consequent rise in the number of people

dying from cancer. Investigations reveal that many GP's are unaware of the specific skills and sources available within a specialist palliative care service, indicating that the service may be accessed inappropriately and used ineffectively. Thus patients who could have benefited from the service are not being referred.

Von Gunten (et al) <sup>8</sup> did not keep specific data on how the improvement in their referrals were achieved. They never had a concerted effort to educate hospital staff, yet a significant amount of education occurred among attending physicians. Their referral base has broadened to include multiple physicians and specialities.

They were of the opinion that the dramatic change in the acceptance of hospice care was mostly influenced by the integration of the program into the hospital under physician direction.

The integration of hospice care into the medical centre took many forms.

- Hospice options for appropriate patients during weekly speciality conferences
- House staff may suggest the option to an attending physician

When a hospice program was made an integral part of an academic medical centre, its acceptance by attending physicians was broad. The authors advocate that hospice practices should be integrated into the general practise setting of physicians.

## **AGREE CRITERIA**

From the literature review there is evidence that all cancer patients should have the opportunity to be partners in a palliative care program from the time of diagnosis.

It was decided to set an acceptable standard for referral as:

- percentage of patients referred as 80% of all cancer patients
- and the time within 2 weeks of diagnosis.

## **METHODS**

### **Observe Practise**

#### **Referral procedures**

At the time of the study, referrals to the palliative care unit were made on a specially designed “oncology referral form” which is usually completed by the medical officer or the houseman of the department. A complete medical report with copies of the histology and/or cytology reports usually follows a few days or weeks later.

The problem is that the initial forms are completed when the patients are discharged from the ward or clinic. The patients are usually not told to make an appointment so as to meet the palliative care doctors, and are only encouraged to come to the unit when they have a problem.

In a small number of cases the patients are referred/transferred to the palliative care unit while they are still in-patients.

It was not known whether all potential patients were referred to the unit. A cancer register is kept in the unit, but it is clear that all cancer patients were not on the register. E.g. a patient would present with a complication from chemo- or radiotherapy. The palliative care unit is notified, but it is then found that the patient is not on our register

### **Measures**

Our current practise was evaluated by means of a retrospective study of referrals to our palliative care unit over a period of six months, covering 1 July – 31 December 2001. A referral rate was calculated using the number of possible referrals as a denominator. The number of possible referrals was taken as all patients who were diagnosed with a malignancy during the same time period. (Patients diagnosed with carcinomas in-situ such as cervical intra epithelial neoplasia, were excluded.)

The time lapse between diagnosis of cancer and referral to the palliative care unit was measured and recorded.

The “date of diagnosis” for surgical patients was taken as the date of the surgery e.g. date of a mastectomy. The investigator found that there were time lapses between the initial biopsy, histological diagnosis and the final surgery.

The date of referral was taken as the date of the first appointment in the palliative care unit. (We often receive letters detailing the case history long after the patient has been discharged from the hospital. Therefore I have decided to use the date of first appointment as referral date, since there is no waiting time for appointments.)

If possible, it was also noted whether these consultations were the result of a problem that the patient or family struggled to cope with.

### **Data Sources**

Initially the investigator planned to consult the cancer register, to compare the number of referrals to the palliative care unit to the number of potential patients in the cancer register. On investigation it was found that the register was not kept by any person and thus incomplete.

Permission was then obtained to access histological and cytological reports of all patients who had biopsies for the period 1 July – 31 December 2001. These records were accessed from computer. The investigator did not access the relevant information for purposes of the audit only, but also updated the hospital's Cancer Register.

The palliative care unit keeps records of each cancer patient, their diagnosis, treatment options, other relevant information and suggestions from their oncologist. As soon as a patient is referred from the physician/surgeon a folder is opened in the unit. If a patient is not referred to the unit, it can be assumed that he/she would not have an oncology folder. The date of referral; the date of the first consultation with one of the palliative care doctors; and the reason for the consultation could be assessed from the oncology records.

### **Procedures**

The findings of this initial assessment were used as a discussion/interview point with the different heads of departments.

Heads of departments are seen as the link between the palliative care unit and the referring doctors, as they are the ones who overseas and take responsibility for the actions taken in their departments.

Approval from the ethics committee was awaited, prior to accessing the records. The interviews could only take place in the middle of April 2002. The department heads of internal medicine, gynaecology, surgery and urology were interviewed. (Appointments could not be set with the department heads of Orthopaedics and ENT, as they were not available at the time.)

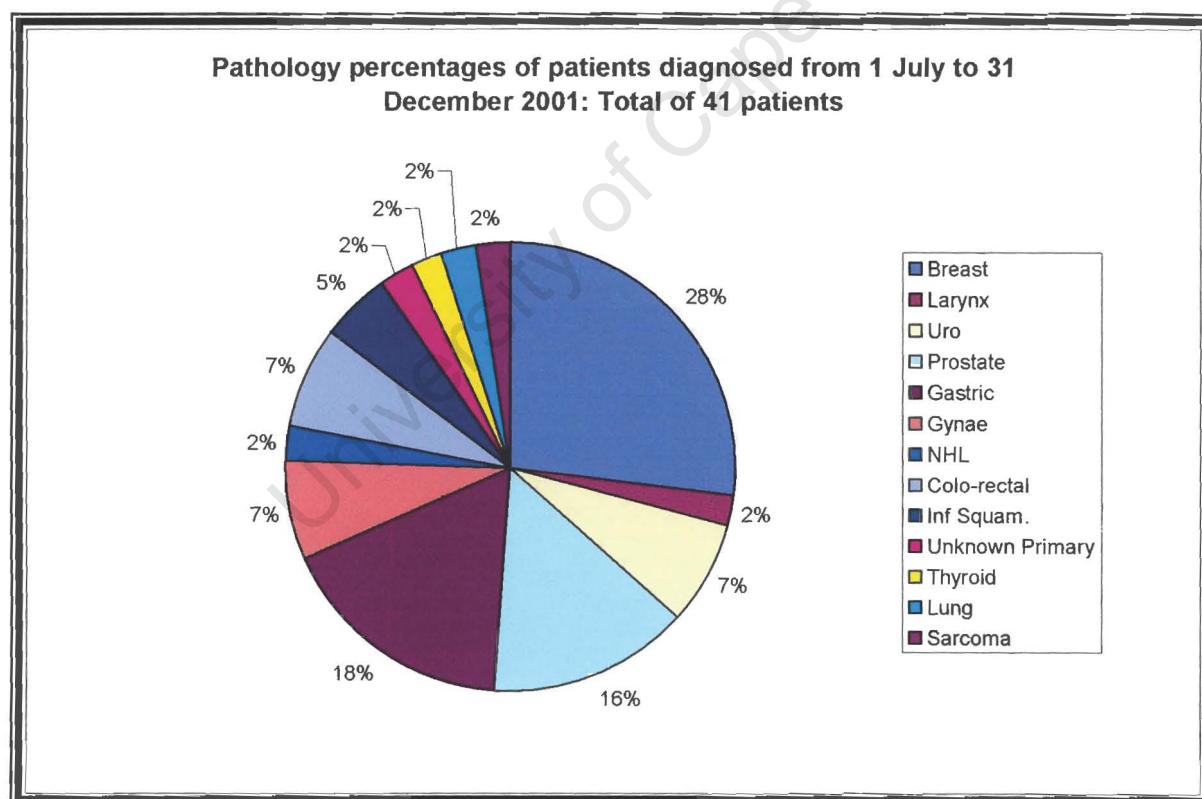
The interviews were recorded with the permission of the interviewee and then typed verbatim.

The interviewees were asked what they thought the reasons to be for not referring cancer patients to the palliative care unit. This was an attempt to recognise possible barriers to referral within the system, or from the doctors' point of views.

They were also asked what could be done differently to improve referrals to the unit.

## RESULTS OF OBSERVED PRACTISE

In the period 1 July – 31 December 2001, a total of 41 patients were diagnosed with cancer. Their diagnosis included breast cancers (11); gynaecological cancers (3); cancers of the lung, thyroid, larynx, unknown primary, sarcoma, and NHL (each 1), bladder and renal cancers (3); prostate cancers (6); gastric cancers (7); colo-rectal cancers (3) and infiltrating squamous cancers (2). This can be seen in the following pie chart.



In this period only 22 patients were referred to the palliative care unit.

**Summary of patients referred to PCU 1 July – 31 December 2001**

| Patient number | Time from diagnosis to PCU consultation<br>In days | Time from diagnosis to death<br>in days |
|----------------|--|---|
| 1              | 2  | Alive                                   |
| 2              | 50   | Alive                                   |
| 3              | 22   | Alive                                   |
| 4              | 7  | 28                                      |
| 5              | 160  | Alive                                   |
| 6              | 66   | Alive                                   |
| 7              | 0  | Alive                                   |
| 8              | 2  | 3                                       |
| 9              | 4  | 39                                      |
| 10             | 6  | 100                                     |
| 11             | 4  | 9                                       |
| 12             | 0  | Alive                                   |
| 13             | 24   | 51                                      |
| 14             | 10   | 11                                      |
| 15             | 119  | Alive                                   |
| 16             | 34   | Alive                                   |
| 17             | 79   | Alive                                   |
| 18             | 103  | Alive                                   |
| 19             | 7  | 27                                      |
| 20             | 27   | Alive                                   |
| 21             | 13   | 27                                      |
| 22             | 30   | Alive                                   |

The time lapse between the diagnosis and referral to the palliative care unit ranged from 0 (the same day as the diagnosis) to 160 days. Only 11 (27%) of the patient were referred within 14 days of diagnosis of whom 3 died within 2 weeks of referral to the unit.

However it must be noted that all three these patients were newly diagnosed patients and that there were no delay in referral of these terminal patients.

Three patients developed problems that prompted them or their families to seek help from the unit. These included a patient and family with psychological and social problems; a patient who developed nausea from chemotherapy and a caregiver who requested admission for the patient, as she/he could no longer cope with the patient at home. (The patient died 14 days after admission).

The above- mentioned findings were used to initiate discussion in the interviews with the different department heads.

## RESULTS OF INTERVIEWS

Interviews with the heads of departments revealed four categories of reasons why patients were not referred.

1. Doctor's perceived barriers from within patients
2. Barriers to referral within the doctors
3. The nature of the cancer
4. The referral system

### **Doctor's perceived barriers from within patients**

Doctors felt that patients did not attend or did not want to attend the palliative care unit for the following reasons.

#### **Denial**

Denial is part of the process of grieving a loss. Doctors felt that patients' use of denial as a defence mechanism precluded their willingness to be referred to the palliative care unit. However denial was not seen as permanent but rather as a step in the overall process.

*"For them (the patients) it would mean admitting to life threatening disease. Maybe the patient was not ready yet to admit that he/she needs hospice care"* (DR. A: 44-46)

### **Patient's autonomy and choice**

Doctors saw patients as having the right to make their own decisions, despite their doctor's recommendations.

*"Now and again the doctor refers a patient but the patient decides not to attend your clinics" (DR. A: 48 –49)*

*"You can not force people to attend your clinic. You must offer a specific service. If you offer a service that nobody else provides...he will want to come to you"*

(Dr. C.: 145 – 148)

### **Patient comes from far away**

As the Military Hospital is a referral hospital for all military patients in the Western, Eastern And Southern Cape, there are some patients from outside Cape Town who would then return home for follow up where their local units and sickbays, as well as their local GP's would be responsible for their care and management.

*"Some of our terminal patients are coming from far e.g. Oudtshoorn. It is of no value getting the palliative care unit involved on this side if the patient is going back to his home." (Dr A.: 77 – 79)*

### **Concern that patients will feel rejected**

Some doctors fear that the patients will misinterpret their referral.

*“The patients will feel that I have rejected them, because I handed them over to you”*

(DR. A.: 84 – 85)

### **Doctor’s concerns about patient’s interpretation of referral to a palliative care unit.**

Doctors were concerned that patients associate referral to the unit with a bad prognosis and that referral will create anxiety. They perceive that there might be a hidden message in the referral and that their doctor might not be honest with them.

*“Some times patients have fears”* (DR. A: 40)

*“ patients will make assumptions e.g. are you hiding something from me or is my condition that bad... 90% of patients will ask when I mention your name, so what are you telling me doctor?”* (Dr. D.: 103 –107)

### **Patients don’t know what the palliative care unit offers**

*“He will just tell you that he does not want to go, but this is usually because of ignorance. Patients often do not know what services you have to offer”* (Dr. A: 40 –42)

## **Barriers to referral within doctors.**

### **Poor marketing of PCU/ Lack of awareness**

This was mentioned by all four of the doctors interviewed. Most of the doctors were not aware of the different functions of the palliative care unit.

*“Maybe you did not promote yourselves well enough. The doctors do not know exactly what you have to offer, what they can not offer” (Dr. A: 61 – 62)*

*“ Could you send me a copy saying ‘we as a the palliative care unit offer the following services’ ” (Dr. B.: 183 – 184)*

*“ You need to make it clear who needs referral... ” (Dr. A: 107)*

*“It is unclear at this stage who you want to see” (Dr. A: 114 –115)*

*“ You must provide guidelines regarding whom you want to see; how you want to see them, the way the follow up works etc. ” (Dr. D.: 31-33)*

*“I am still uncertain with the way your appointments work” (Dr. D.: 54)*

*“Many of the doctors do not know what you have to offer” (Dr. D: 74)*

*“ Maybe you must sit down with all of us and say, this is our vision, this is where we want to be involved” (Dr. C.: 124-125)*

*“You need a modus operandi. It is important to ensure continuity” (DR. C.: 137)*

### **Doctors do not want to "dump"**

At times, some doctors shift their responsibility for a patient inappropriately. This is commonly known as “dumping”. . For some doctors, referral to a palliative care unit can be seen as a negative action of inappropriate shifting of responsibility

“People see the unit as a dumping ground. If they do not know what to do with a certain patient, the patient ends up with you” (DR. A: 102 –104)

### **Professional commitment and satisfaction**

A sense of commitment to the patient and professional satisfaction of ongoing care was evident. *“I must admit that there is a reluctance to refer some patients. I want to do the follow up of my breast patients myself”* (Dr A 82 –83)

“ We feel that we have walked a path with the patient and do not wish to hand over the management to somebody else” (Dr A: 86 – 87)

*“ You do not want to shift the responsibility to somebody else”* (Dr. A.: 88)

### **Perceived lack of need to refer**

For some doctors, who feel that they have the requisite skills, referral to a PCU may be seen as unnecessary.

*“There might be a few doctors who think they are clever enough taking care of the patients”* (Dr. C.: 93)

### **Doctors may make incorrect assessments regarding patients needs**

The referring doctors have to assess the patients to see whether the patient warrants a referral to the palliative care unit. One doctor felt that doctors might incorrectly assess the need for referral.

*“Sometimes the doctor screens a patient. Sometimes he is correct, but sometimes he makes mistakes” (Dr A: 55 –56)*

### **Single discipline rather than referral to the unit as a team**

Some doctors are not aware that the palliative care unit functions as an interdisciplinary team.

*“There are a lot of patients who have social problems, they are referred to the social worker or to the psychiatrist” (DR. A: 69 –71)*

*“I think that there are well defined functions of different units e.g. the hospice has this function; the dietician this, the psychiatrist this, the physio this... If the Hospice unit marketed themselves as a multi-disciplinary team, that co-ordinates all the different functions, it would be much easier for the referring doctor.” (DR A: 72 –76)*

*“ You have a psychologist there? Who else do you have?” (DR. B: 47)*

### **Perceptions of most appropriate use of resources**

The palliative care unit is also responsible for patients who are receiving rehabilitation after surgery, stroke and spinal cord injuries. One doctor was concerned that time spent with cancer patients would detract from the care of patients who need rehabilitation.

*“ The problem is that you cannot consult each and every patient that was diagnosed with cancer, because you will not be able to do your rehabilitation duties” (Dr. D.: 33 – 35)*

## **Image of the work of the PCU**

### **Care of the 'social aspects'**

The responsibility of the unit was seen to be care of the "social aspects" of patient care.

"Someone may have be required to go to Groote Schuur Hospital, but there may be no one at home to look after the kids for the family. And I think that is where you guys come in." (Dr. B: 69 – 70)

One doctor felt that only patients with advanced disease required the services of the PCU and he saw the role of the unit being to support the family. His use of the words "those things" seems to reflect his uncertainty about what the unit can actually do.

*"The patients with the advanced disease are the ones you need to see regularly for family support and those things"* (Dr. D.: 43)

One of the doctors saw the palliative care unit as having more time to counsel patients than the staff of his unit had. (Note the difference form the doctor quoted above who felt that the PCU did not have enough time to attend to cancer patients given their commitments to care for all the rehabilitation patients.)

*"Sometimes the doctors have not got enough time to see the patient, to counsel, to discuss issues, family issues"* (Dr. B: 67 – 68)

## **2 Military Hospital's palliative care unit is not typical of palliative care units**

*"You are also playing a facilitating role [in the patients with curable disease]"*

(Dr. A: 8)

### **Palliative care referral creates hope**

One doctor saw the unit as "creating hope".

*"Oncology patients feel that ' I am going to get treatment and support' and it is creating a sense of hope"* (Dr C: 89 –90)

### **Palliative care is seen as the same as Hospice**

Many doctors saw the palliative care unit as a hospice for the terminally ill, implying that referral to the palliative care unit, even in the early stages of the disease requires acceptance of a terminal disease.

*"Maybe the patient was not ready yet to admit he/she needs hospice care"*(DR. A: 45-46)

### **A palliative care unit is a luxury**

*"I see it as a luxury to have a palliative care unit"* (Dr A: 99 – 100)

### **Fear of involving families**

Doctors were told that the PCU involves the family from the start. This was viewed with concern by one doctor:

*"Involving the husband and children...the patient herself may be too shocked, she is still trying to come to grips with the diagnosis"* (Dr. B.: 112-113)

One doctor felt strongly that family has a responsibility to provide care which allows loved ones with terminal illness to die peacefully at home, and that if one offered palliative care the family would abdicate their responsibility to the detriment of the patient.

*“Some relatives got a tendency of dumping patients in a hospital. Some people don't accept the idea of people being allowed to die in peace at home.” (Dr. B.: 131 –132)*

### **Referral is seen as the job of junior doctors**

As in most hospitals, the junior doctors are usually responsible for the paper work and administration in the department. Often they are not the doctors who made the diagnosis, but are still given the responsibility of referring the patient. It could easily happen that a patient fails to be referred. This may be due to poor communication between the doctor who makes the diagnosis and the junior doctor.

As junior doctors are also rotating between departments, they might not be aware of the system or their responsibilities and thus not refer patients unknowingly.

*“The junior doctors are responsible for the administration of referring patients. It is very seldom that the consultants do the referrals themselves” (Dr A: 64 –66)*

*“The medical officer must take the responsibility to inform you (PCU)” (Dr. D.: 28 –29)*

*“It is the department head’s responsibility to inform the medical officers about it (the referral system), but they change so often that you do not verify that they know how the system works” (Dr C.: 29 –32)*

### **Staff shortage**

Although useful means of communication had previously been in place, staff shortages placed limits on this.

*“ At one stage we did send a MO to attend the oncology ward round (in the PCU) to give feedback and referrals through to you. At this stage we area bit out of MO’s, but that worked well.” (Dr. A: 144)*

### **Lack of feedback**

Doctors felt that feedback on the progress of patients they had referred would encourage future referrals. Feedback was seen as a very powerful motivator.

*“ If we could hear a bit more from you, ... you take the patients further, but the patient is lost to us” (Dr. C.: 48 – 50)*

*“Giving feedback is an important element.. When we hear from you again, it is such an awareness that is created, that you do not want to disrupt the process” (Dr. C.: 60 –63)*

## **Nature of the cancer**

Some cancers do not warrant palliative care

*“ The most likely reason for a doctor not to refer a patient is if he/she thinks that it is not indicated e.g. a localised skin cancer that is excised completely” (Dr.A: 50 –52)*

*“ That (referrals) will obviously depend on the stage of the patient” (DR. B. 8)*

*“ I feel that if a patient has localised disease he does not have a place in the palliative care unit yet” (Dr. D.: 39 –40)*

## **Referral system**

### **Referral cards not available**

The reason for non-referral can be as simple as the non-availability of the referral card or form.

*“There used to be cancer referral forms, but you do not see any of these around in the clinic any more” (Dr D.: 19 – 20)*

### **Lack of teamwork in referring departments**

One doctor felt that other members of staff should remind the doctor to refer the patient.

Although this might initially sound like a shifting of responsibility it also shows that staff are not optimising the potential benefits of teamwork.

*“I can also state that I never had a nursing sister or staff member that would remind me to refer a patient to the oncology department. I think they are also part of the team, and should also, play a part in the system” (Dr. C.: 38 –42)*

### **Doctor’s sense of confusion with regard to the system**

At the military hospital the PCU is responsible for a number of administrative duties with regard to patients with cancer. This allocation of responsibility is unclear and a need was clarification was requested.

*“We need to define who is responsible for what” (DR A: 81)*

*“ Who does the referral (to GSH)? We actually thought that we were doing the referral.*

*(Dr. B: 28)*

*“I do not know if this is something new and necessary if I am doing it in any case”*

*(Dr. D.: 11-12)*

### **Suggestion given by doctors for the future**

#### **Joint ward rounds or academic discussions**

When I suggested that staff of PCU join departmental ward rounds, it was felt that this would not be an effective use of time for the PCU staff given the paucity of patients with cancer.

*“I could give you the times of the rounds, but there will be days that we see 20 patients and not one is an oncology patient.” (Dr. A.: 149)*

*“We have academic discussions, we usually take an interesting patient, but it is not necessarily a cancer patient.” (Dr. A.: 132 –133)*

Overall the referring doctors were quite positive about having the palliative care doctors attend their ward rounds and discussions.

*“We’ll actually be clever to ask you to join us on the ward round and after which we can discuss the way forward and what we are going to do” (Dr. B: 89 –91)*

*“We can try some of our academic meetings...we can present an interesting patient, that we have diagnosed and referred to you” (Dr. C.: 114 – 117)*

### **"Advertise" services offered**

Three of the four doctors suggested that all the referring doctors be informed on the services that the palliative care offers.

*"If you could just send us a copy saying we as a palliative care unit offer the following services" (Dr. B.: 183 – 184)*

*"If the hospice unit marketed themselves as a multi- disciplinary team that co-ordinates all the different functions it would be much easier for the referring doctor" (Dr. A.: 74 – 75)*

*"If you offer a service that nobody else provides in an environment that is safe and comfortable the patient will want to come to you" (Dr. C.: 147-148)*

### **Doctors want guidelines or protocols**

*"Doctors do not know what your field of expertise are. You have several subdivisions e.g. pain control, rehabilitation, and terminal care. You need to make it clear who needs referral...you need guidelines" (Dr. A.: 105 – 108)*

*"Maybe you must sit down with all of us and say: this is our vision, this is where we want to be involved, and this is how we operate...." (Dr. C.: 124-126)*

*"You need a modus operandi...it is an important principle to ensure continuity"*  
(Dr. C.: 137)

*“You must provide guidelines regarding whom you want to see, how you want to see them and the way the follow up work” (Dr. D.: 31 – 32)*

### **Changes to the referral card**

One doctor suggested required more detailed information on the referral card.

*“I would suggest that you get a similar type of card, but instead of only giving the history, to also specify the reason for referral e.g....support... terminal care.... preparation for terminal disease.... psychological support...pain control”*

(Dr. D.: 63 –70)

### **PCU should give more feedback**

*“Giving feedback is an important element. When we hear from you again, it is such an awareness that is created, that you do not want to disrupt the process” (Dr. C.: 60 –63)*

### **Ideas on getting patients to accept PCU**

*“If you describe the circumstances and the way the ward works, and what you have to offer there is usually a change in attitude” (Dr. C.: 89 –90)*

*“ Patient information sheet.... you can highlight what your services is all about and why he/she was referred to the PCU” (Dr. D.: 113 –114)*

## DISCUSSION AND RECOMMENDATIONS

From the interviews the following conclusion and recommendations could be made.

### Denial

Doctors cited denial by patients as a reason for their reluctance to attend the PCU. Denial is a normal, but potentially transient, part of the grieving process. If this is understood then the team's role can be to help the patient work through the denial, rather than accept denial as permanent.

Denial as a reason for not attending a hospice has been shown to be a reality. A survey by Navari and Stocking<sup>10</sup> found that a majority of patients with advanced symptomatic cancer rejected the recommendation for palliative care and requested additional interventional treatment; even when they were told that non-hospice alternatives would not increase their survival and hospice care would focus on quality of life care with good symptom control. They concluded that patients often choose not to go to a Hospice because they have difficulty in accepting the diagnosis.

Despite this evidence of patients' denial as a barrier to seeking care, it is possible that doctors may project their own denial on to their patients. This may reflect the doctor's own defence against feelings of helplessness in giving a poor prognosis to the patient. Franks has put forward the idea that the diagnosis of incurable disease is perceived by some doctors as a failure on their part.<sup>11</sup>

Recommendation:

Encourage doctors to see patients' denial as a normal and necessary, but potentially transient, part of the process of grieving

Help doctors to develop skills to work with patients who are in denial

Help doctors to recognise and deal with their own feelings around their inability to cure all of their patients

### **Patient's autonomy and choice**

Doctors saw patients' autonomy as important. It is one of the four principles in medical ethics.<sup>12</sup> If the patient has autonomy he/she can make his/her own choice on the basis of deliberation. However, in order to make an informed choice the patient needs to be informed of the options. If the referring doctors do not know the palliative care unit's functions it can not be expected that the patient will receive sufficient information with which to make the choice.

Recommendation:

1. The palliative care unit must ensure that all the referring doctors are aware of the function of the PCU and pass on this information to patients. If a patient still chooses not to attend the PCU, that choice should be respected.

### **Some patients come from far away**

It is a misconception that patients from smaller centres do not require palliative care. By the palliative care team making an initial needs assessment of the patient, a management plan could be established and the responsible doctor at the local sickbay could be assisted in managing the patient at home.

## Recommendation

1. Doctors need to know that even patients from smaller centres need to have a formal assessment of palliative care needs before being discharged to their local doctors.

### **Concerns that patients will feel rejected**

This concern emphasises the doctors' perception that they are not sharing in the responsibility of managing the patient diagnosed with cancer, but rather "are handing them over" to the palliative care unit. This is the attitude that we hope to change and to address with this audit.

This concern of rejection could perhaps be a form of transference on the part of the referring doctor who feels about not being able to cure the patient.

### Recommendation:

1. Encourage doctors to share management with the palliative care team.
2. Encourage doctors to be aware of their own feelings associated with the diagnosis and management of non-curable diseases.

Doctor's concerns about patient's negative perceptions of referral to a palliative care unit.

Doctors were concerned that patients associate referral to the unit with a bad prognosis and that referral will create anxiety. This concern might imply that the issue of terminal or incurable disease was not discussed with the patient; otherwise it should not even have been a concern with the referring doctor.

“Bad news” has been described as information that drastically alters a patient’s view of the future for the worse.<sup>13</sup> Being the bearer of bad news is distressing and doctors may be unwilling to carry this. This concern seems to reflect the doctor’s wish to protect the patient and can be seen as part of the doctor’s own denial.

The doctor’s unwillingness to refer the patient will result in the patient missing out on aspects of care and also maintain a collusion of avoidance. The patient may respond to the doctor’s avoidance of sensitive topics by avoiding them him or herself and this will impinge on open communication within the doctor-patient relationship.

In gently confronting, rather than avoiding painful issues, the fears of patients can be addressed. Those involved in the care of the patient and the family need to understand the patient’s and the family’s perception of the disease process. It is also important to know if the patient or the family have experienced a similar situations in a close relative, since any horrifying experience may compound a patient’s own fears.<sup>14</sup>

It is important to be aware that the more frightened a patient is, the less likely he or she is to talk about the fears.

**Recommendation:**

1. Breaking bad news is an important skill for all doctors and needs to be taught and practised and subjected to ongoing reflection
2. Doctors need to come to terms with their own mortality and vulnerability in order to confront, and help patients deal with, their mortality.

3. Helping patients to confront their fears requires the doctor to explore the patient's concept of the disease and concerns.

Finlay<sup>14</sup> states that it is important to acknowledge the fear in the patient and the family and to reassure the patient of the doctor's commitment to care.

### **Patients don't know what the palliative care unit offers**

This is one of the major barriers that were identified. As mentioned previously, a patient can only make an informed choice to attend the unit after consideration of all relevant information.

As one of my own patients remarked: *"One of my friends was very negative when she heard that I was attended to by your unit. She told me to 'get out of this unit because I will die in here'. When I told her that this was not the case and explained what you do, she was amazed..."*

*Doctor, I think you must write an article so that all the people know what your unit is about..."*

Recommendation:

1. A patient information sheet with explanations of the different functions of the unit; answers to possible question that could be raised and the contact details of the unit would help patients to know what the PCU can offer and alleviate unnecessary fears. These can be handed to the patient with the first consultation by PCU staff while the patient is still in the ward.

2. Patients rely on support and advice from their friends and family. The broader military public needs to be informed. An article on palliative care in one of the military's monthly publications, to inform the military public of the functions of our unit would give information to people who are well and also friends and families of patients.

### **Lack of awareness of the field of palliative care among doctors**

Palliative care is a new field in South Africa. Most doctors did not have palliative care training as pre-graduate students. Also, not much has been said or written in South African medical journals. It is therefore understandable that most doctors are not aware of the functions of the palliative care units in general.

Although palliative care is now taught in the curriculum of pre-graduate students, only a few students have the opportunity to rotate in a Palliative care or Hospice environment. This is due to palliative care units not yet being part of teaching and general hospitals, and are managed in the private sector. Sadly these smaller facilities are not able to accommodate all medical students and it is fact that awareness is created/boosted by exposure.

As 2 Military Hospital is not a teaching hospital and most of the doctors have had no exposure to palliative care, the palliative care team has the responsibility to create awareness among all health care professional in the hospital.

### **Recommendation:**

1. Work together with local universities to allow more medical students the opportunity to rotate in a palliative care setting.

2. Encourage postgraduate training in palliative medicine in all the different disciplines, as all doctors can use the knowledge obtained in improving the care of their patients.
3. Compile a short palliative care workshop to be attended by a representative of each referring department to emphasise awareness and the functions of the unit.
4. Make use of the annual national “Hospice week” to encourage palliative care awareness among medical staff. (and encourage doctors to attend these)
5. Compile a short notice or information sheet for distribution in the different departments, informing doctors on the different functions of the unit.

#### **Doctors do not want to "dump"**

The PCU believe that there is no such thing as “dumping”. We feel that there is something that we can offer any patient whom is referred to us. The referring doctors are not aware of the different functions in the unit, or the care that the unit can offer, they could see it as a “dumping ground” as the one doctor has pointed out. However, no patient in any stage of a disease process is beyond the point where care cannot and should not be offered. Especially when there are no more curative options for a patient, palliation can still be offered.

An aphorism of an unknown author defines the role of a physician as:

*“ To Cure Sometimes*

*To Relieve Often*

*To Comfort Always”<sup>2</sup>*

Again the question should be raised whether this perceived barrier to referral is not an issue of the doctor feeling guilty because he/she cannot offer curative care.

Recommendation:

1. Doctors need to be reassured that referrals are welcomed and something can be done for almost every patient.
2. Palliative care should be emphasised as active management in patients with incurable disease.
3. Doctors should be aware of their own feelings in managing patients with life-threatening disease.
4. The ethos of working as a team needs to be established, and encouraged in order to avoid concepts such as dumping.

### **Professional commitment and satisfaction**

This perceived barrier to referral is a result of the lack of insight regarding the shared management of cancer patients. The dedication and commitment of doctors to their patients should not be criticised but applauded. It is admirable that specialists with busy schedules still wish to provide care for potentially terminal patients.

Recommendation:

1. The palliative care team must emphasise the concept of shared care. This would include better communication between the palliative care unit and the referring doctor.

### **Perceived lack of need to refer**

There are patients with terminal diseases that will never require the specialised services of a palliative care unit as their symptoms are controlled and they are psychologically at peace and have come to terms with their situation. However arrogance on the part of the doctor may also play a role. As Finley <sup>14</sup> states "*it would be foolish, and even arrogant, for any one physician to feel that he or she can provide everything for a patient...*" The opposite is also true, that the palliative care team should guard against the arrogance of not acknowledging the special skills and talents of doctors in other disciplines offering palliation despite their lack of formal palliative care training.

#### **Recommendation:**

1. Doctors can be encouraged to see referral, not as being a reflection of their lack of competence, but rather a way of including other team members who may be able to offer something more.
2. The palliative care team must guard against arrogance and unwillingness to acknowledge the expertise of the referring physicians. However, although the referring physician will be able to provide excellent care, there might be another discipline in the multidisciplinary team that can offer assistance to the patient. Therefore even the very skilled physician should still be encouraged to refer to the palliative care team, even if it is only for the sake of exposure to the other disciplines.

### **Doctors make incorrect assessments regarding patients needs**

Doctors sometimes underestimate the needs of patients for care beyond the physical.

It has been described in literature that general doctors set fewer goals for patient care and usually do not emphasise the psychological, emotional, spiritual and social needs of the patient with incurable disease.<sup>15</sup>

#### **Recommendation:**

1. A deeper understanding of the needs of patients with cancer, beyond just the physical, needs to be inculcated in doctors. These needs do not all need to be met by one individual, but managed by a team of people from different disciplines.

### **Referral to a single discipline rather than referral to the unit as a team**

The patient with life-threatening disease has to face numerous issues including a new body image, a new role in the family and society, the uncertainty of the future and many more. To understand the physical, emotional, spiritual and social needs, requires a range of skills.

This variety of skills is usually incorporated in the interdisciplinary team. The team share a common goal i.e. to improve the quality of life of the patient. The members usually share information and work interdependently together to develop goals.<sup>2</sup>

By referring the patient to a single discipline, rather than the interdisciplinary palliative care team, the opportunity for shared care could be undermined and the patient could miss out on a wonderful opportunity of care.

Recommendation:

1. Doctors should be encouraged to refer the patient to the interdisciplinary team. The possible benefits of shared responsibility should be emphasised.
2. Doctors could be released of the responsibility of referring to each different discipline separately, thus saving time. As palliative care team meetings are held weekly, the different members of the team can be informed of the patient at such meeting.
3. The members of the interdisciplinary team should be encouraged to attend the meetings regularly, as the meetings are important in information sharing and developing goals for each patient.

#### **Perceptions of most appropriate use of resources**

The palliative care unit is combined with the rehabilitation unit. One doctor was concerned that time spent with cancer patients would detract from the care of patients who need rehabilitation. He could have implied the fourth medical ethical element of justice i.e. “the patient should have the best possible care within the sources available, but also these resources must be justly allocated for the community they serve to maximum benefit”<sup>12</sup>

This is an important ethical principle, but the opposite is also true i.e. if the resources and the manpower are available, it is an injustice not to refer the patients.

Recommendation:

1. PCU needs to clarify that they are able and willing to see all patients with cancer, despite ongoing responsibilities to patients in the rehabilitation unit.
2. In a developing

country like South Africa, palliative care should be emphasised even more as resources for curative treatment are often lacking. Palliative treatment and care are often the only options for care in life-threatening diseases and patients should not be denied access to it, because the doctor seems to be too busy in taking care of them.

### **The Image of the Palliative Care Unit**

#### **Care of the “social aspects”**

The palliative care unit does take responsibility for addressing the social needs of the patient. However there remains the risk of separating the biological from the psychosocial aspects of care. i.e. one doctor will look after the physical needs, but the palliative care unit will address the social issues and “those things” which usually are the more personal and difficult to address.

The term “those things” could be an indication of the uncertainty doctors experience when addressing the less clinical aspects in caring for a patient with life-threatening disease, as they are usually not clear cut, and not easy to solve.

We believe holistic care is more than the sum of the parts of caring for various aspects of a patient. It describes an approach that brings with it a particular kind of healing relationship. A relationship of trust is built with a patient through attention to physical needs and lays the basis for an ongoing trusting relationship in which more personal issues can be expressed and worked with.

Recommendation:

1. Doctors need to be informed that patients should be referred to PCU not just when there are social problems but as soon as possible after diagnosis so that a therapeutic relationship can be formed with the PCU team.

### **Palliative Care is seen as Hospice**

Many doctors saw the palliative care unit as a Hospice, that only offer treatment in the very late stages of the disease. Palliative care does include the aspects of hospice care in the terminal phase, but has much more to offer to the patient earlier in the disease process.

Recommendation:

1. The ward is called "Hospice" and to address the confusion, it will be changed to "Palliative Care Unit".
2. Through sharing information on the different aspects of care and the functions of the unit, the concept of palliative care would be extended.

### **2 Military Hospital's palliative care unit is not typical of palliative care units**

Our unit is involved with patient care from the stage where curative treatment is still offered. Weinstein has described the benefits of the implementation of a palliative care program into an oncology center, and the achieved quaternary prevention that was achieved i.e. the prevention of suffering associated with the disease. <sup>4</sup>

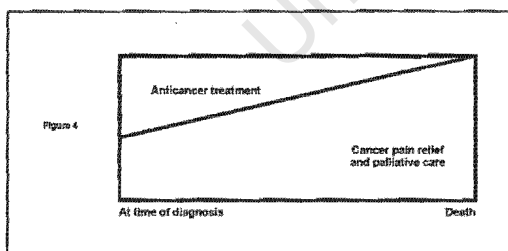
Thus this might not be as unique as we thought.

## Recommendation.

1. Emphasise the role that the palliative care can play in the phases where cure is still an option. This role could be the insurance of good communication between the treating doctors and the patient.

### **A palliative care unit is a luxury**

The view by one doctor of palliative care as a luxury given the current budget cuts needs to be challenged. The concept of palliative care is still in the early stages of development in South Africa, with only a few established palliative care centres and clinics. The limitations in the budget mean that less curative care is available and therefore even more people require palliative care. Although people and maybe government can see it as “an extra” or “luxury” as the doctor commented, it is a necessity. In a developing country like ours, there are often no resources to offer curative treatment and the only option to offer to the patient is palliative treatment. As can be demonstrated in the following figure from the Oxford Textbook of Palliative Medicine.<sup>2</sup>



Because of limited resources for curative intervention, palliative interventions should be offered much earlier in the disease process

Furthermore, although this study has only included care of cancer patients, it is a fact that rising numbers of patients with HIV/AIDS will require these units in the near future.

Palliative care also serves a preventive function. In addition to the prevention of suffering, complications can be avoided. Examples of this are prevention of constipation, which will cut down on urgent admissions for faecal impaction, teaching a family about home care of a bedridden patient prevents admission and possible surgery for bedsores.

Recommendation:

1. We need to extend the idea of palliative care as essential care both in terms of prevention of suffering and in terms of cutting costs.

#### **Administrative functions of the palliative care unit at 2 Military Hospital**

If a patient is referred to an outside facility for therapies such as chemo- or radiotherapy, current bureaucracy requires that a letter of authority be signed for each visit. Treatment will not be given without this as it serves as proof that payment will be made.

The PCU functions to treat the complications associated with the therapy; and liaises with the hospital providing the service. For example the PCU needs to order specific medication prescribed by the treating hospital. In addition the PCU is responsible for conducting blood tests and other investigations before the patient is referred for each dose of chemotherapy.

Recommendations:

1. Doctors have to be informed of the administrative function of the PC unit. The referral for curative treatment is usually not a function of a palliative care unit where non-curative treatment is implied. The requirement by Groote Schuur Hospital for a letter of authority for each dose of chemotherapy needs to be challenged and a more streamlined system implemented.

### **Fear of involving Families**

(Definition of family: those individuals considered as family by the patient)

It is important to stress that a disease like cancer affects the whole family. Disease does not occur in a vacuum, as most individuals are members of a social network. The manner in which a patient's family responds to him or her and the illness, may in part determine the patient's response to the disease.

It is assumed that if the family's needs are handled well from the time of the diagnosis, then with the final outcome (even if it should be death) the problems will be fewer and less complicated than would be the case if there were unresolved issues during the early stages of the disease.

Family activities, roles and relationships become altered after the diagnosis of cancer.

Palliative care has the ability to prevent family crisis and create cohesion. Family intervention is therefore needed to confront physical and emotional issues associated with palliative care.

One doctor felt strongly that family has a responsibility to provide care which allows loved ones with terminal illness to die peacefully at home, and that if one offered

palliative care the family would abdicate their responsibility to the detriment of the patient.

This is a misconception that palliative or hospice care implies that the patient has to die as an inpatient in the hospital. Most palliative care units and hospices have community-based staff that assists the families at home. Unfortunately our unit does not provide home-based care at the present moment, but we support the ideals of home-based care. Currently we work together with private hospices e.g. St Luke's to visit our patients at home and advise the family if needed. Also, from our experience, if there is good communication between our unit and the family, the family often copes very well with available telephonic assistance only.

However, families often fear that "their care are not good enough for the patient" and therefore feel that it is inferior to what an inpatient unit can provide. Therefore the families need regular reassurance and acceptance from the health care professionals.

Recommendations:

1. Regular family conferences can explore and address issues concerning the patient and the family members needs.
2. Family members should also be offered individual counselling and support when necessary as they are also facing losses and new roles in the disease process.

3. Patient's autonomy and choices should always be considered and if he/she does not want the family members involved, it should be respected. However the benefits of family involvement as part of the team should be emphasised.
4. The role of the palliative care unit should be explained in home-based care. It should be emphasised that the patient's wishes would be respected as far as possible and that if the patient wished to be at home, the unit will offer guidance and assistance to the family as far as possible.
5. Cultural issues such as dying at one's place of birth should be respected and assistance should be offered to transfer the patient home. Again the palliative care team has a role to play in advising the family on management at home as often these are rural areas, out of reach of medical and palliative services.

#### **Referral is seen as the job of junior doctors**

It has to be kept in mind that the responsibility for referring cancer patients can be delegated to the junior doctors, but accountability not. It might be true that the senior medical doctors do not always have the time to refer patients and therefore delegates the task, but this does not free the senior staff of their accountability when patients are not referred.

#### **Recommendation:**

1. The consultants or heads of departments should be reminded of the responsibility to inform junior staff working in their departments, on the referral system in place.

### **Staff shortage**

Although useful means of communication had been in place, staff shortages placed limits on this.

We do not have the power to appoint more staff; therefore we have a responsibility to do the utmost best with available resources and manpower.

#### Recommendations:

1. In future, attendance of the different ward rounds, by one of the palliative care doctors, can be valuable in the communication between the different departments. As the referring departments are lacking in enough staff, the palliative care unit will be able to manage this arrangement.

### **Lack of feedback**

It should be established what the referring doctors would want to hear and how they want this information to be shared.

The bottom line is that communication between the different departments is not optimal at the moment

#### Recommendations:

1. Create opportunities to communicate e.g. interdepartmental sessions at regular intervals, where feedback can be given and information shared.

### **Some cancers do not warrant palliative care**

We agree that localised cancers e.g. basal cell carcinomas, squamous cell carcinomas, localised prostate or bladder cancers do not warrant a referral to the palliative care unit unless there are administrative functions required as discussed above.

### **Referral cards not available**

The reason for non-referral can be as simple as the non-availability of the referral card or form.

#### **Recommendation:**

1. The PCU ward secretary is allocated the task of ensuring availability of referral forms in all the different referring departments. She will check that the clinics have forms available at all times.

### **Lack of teamwork in referring departments**

The question should be raised whether all medical staff, including the nursing staff, has a voice in their departments.

Again the benefits of working as part of a team should be emphasised. This would enrich the department with diversity and talents within the team, to the benefit of the patient.

#### **Recommendation:**

1. The palliative care team cannot dictate communication within other departments, but can share their own positive experiences of teamwork. Hopefully this can lead to better

communication and shared responsibilities in all departments, with the final aim to benefit the patient.

#### **Doctor's sense of confusion with regard to the system**

This last barrier was basically a practicality. The confusion regarding who is taking care of who and when, should be cleared once the information sheet on the different functions of the unit is handed out and the referring doctors understand the role of the palliative care unit.

#### **Suggestions by referring doctors**

As most of the suggestions and recommendations have been included in the above-mentioned sections, not much more can be added.

#### **Joint ward rounds or academic discussions**

Overall the referring doctors were quite positive about having the palliative care doctors attend their ward rounds and discussions.

#### **"Advertise" services offered**

An information sheet, outlining the different function of the unit was handed out to the different departments, with some positive remarks from some disciplines.

The question was raised by a staff member who is not a medical doctor, whether he/she can refer a patient if he/she feels that the patient will benefit from palliative care.

Recommendation:

This will have to be addressed cautiously, as it could be considered unethical to refer a patient to our department without the knowledge of his/her responsible doctor.

### **Doctors want guidelines or protocols**

Formal guidelines and protocols will be compiled in future. As this is a process that needs discussion and input from all different departments, and is not to be done hastily. For the purpose of this study, an information sheet was compiled until more formal measures can be put in place.

### **Changes to the referral card**

It was suggested that the referral card should have more detailed information. After consideration and discussion with other team members, it was decided to keep the referral card as it is. It was decided to keep it as simple as possible, ensuring that the doctor will not see it as a time consuming activity to complete it.

### **Conclusion to the interviews:**

#### **Comparisons between Palliative Care and post modernism:**

During the interviews various underlying themes emerged. New palliative care involves a number of paradigm shifts, which are consistent with, or can be described in terms of, post modernism.

Post –Modernism developed as a reaction against Modernism and refers to a change in attitude and thinking in the late 20<sup>th</sup> century. <sup>16</sup>

In contrast with the reductionist bio-medical model, post modernism offers a holistic, bio-psycho-social model. Emphasising subjectivity and personal responsibility in each individual. The individual is seen in context and not as an individual in isolation.

| Modernism                      | Post modernism                   |
|--------------------------------|----------------------------------|
| Reductionist bio-medical model | Holistic bio-psycho-social model |
| Objectivity                    | subjectivity                     |
| 'disease' concept              | 'person' concept                 |
| Individual in isolation        | Individual in context            |
| Rules                          | Personal                         |

In palliative care a holistic approach is adapted, addressing physical, emotional, spiritual and social needs. Autonomy is respected and the patient is given choices in his/her disease management.

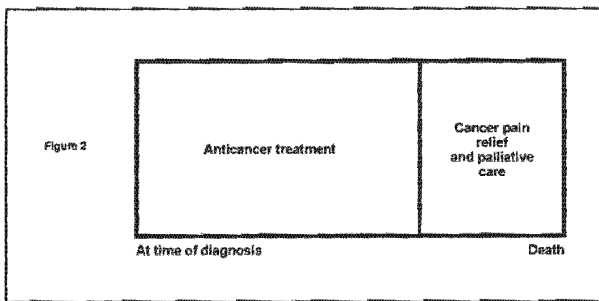
Although most doctors are aware of this approach in their day-to-day interaction with patients, they should guard against the paternalistic approach of deciding what is best for their patients. As well as being aware of needs other than the physical, i.e. the spiritual, emotional and social.

#### **Shared responsibilities between the departments.**

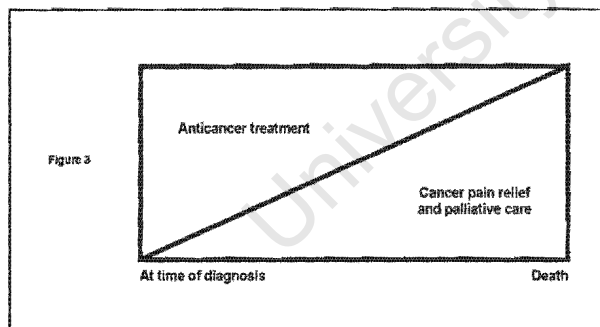
Palliative care is not an alternative to life-prolonging or curative care. It is directed at managing the symptoms of the patient and giving support to both the patient and the family. This support should be delivered in conjunction with curative efforts where appropriate, which could be offered by the individual departments.

The concept of the referring department making the initial diagnosis, doing the surgery and then “handing the patient over”, is therefore a perception that needs to change. The palliative care unit should be seen as part of the general medical team, initially playing a smaller part in the process, and gradually taking over the responsibility of caring for the patient.

This could be illustrated by the following diagram from the Oxford Textbook of Palliative Medicine:<sup>2</sup>



The old perception that needs change: referring the patient to the PCU, only when there are no more options left for curative management.



The new concept of palliative care: being part of the medical team from the day of the diagnosis. Initially playing a very small part in the management of the patient.

The image and expectations regarding palliative care requires a change or paradigm shift within the minds of the referring doctors. This will only happen once the knowledge and

attitudes regarding palliative care have changed and this change will only come with positive experiences and repeated shared information.

The palliative care unit has a responsibility to promote the image of this field of care amongst their colleagues.

### **Palliative care as a process – not just terminal care**

The patients and the family members of patients with life-threatening disease should begin palliative care discussions early in the diseases process, in order to prepare them physically, emotionally, spiritually and socially and to ensure quality of life. The unpredictability of outcomes of patients with life-threatening diseases warrants the involvement of the palliative care team early after the diagnosis.

Palliative care services are provided along the continuum of care from the acute care, to the ambulatory, to long-term care and finally should include hospice care. In the end patients who received palliative care along this continuum are more accepting of the transition into hospice care.

## IMPLEMENT CHANGE

After discussions with the different department heads, the following changes were implemented.

The different department heads would inform their department's doctors about the services of the palliative care unit again. From their side they would try to improve the referring system and refer the patients while they were still in hospital.

The palliative care unit would take responsibility for designing a patient information sheet and a doctor's information sheet. In both sheets the different services of the palliative care unit were explained.

It was stressed that palliative care is not only indicated for patients in a terminal phase of disease. These information sheets were available for distribution from the beginning of July 2002.

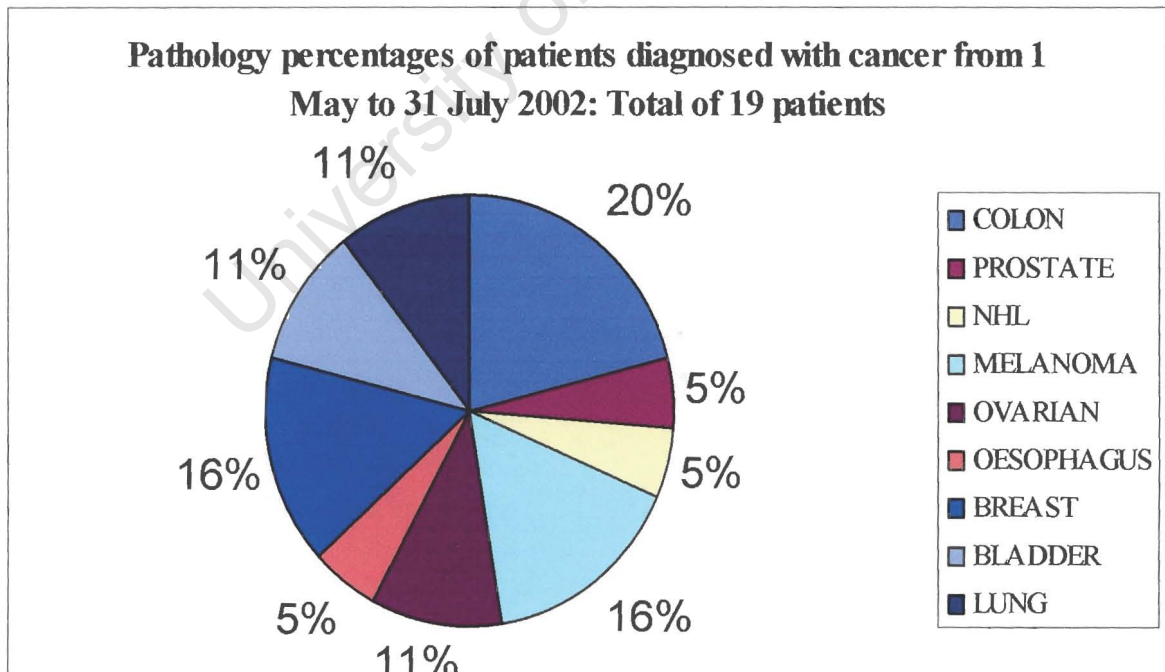
An effort was made to make contact with patients whilst they were still in the ward. One of the palliative care doctors would visit the patient in the ward, after a phone call or short referral from the department. The palliative care doctor would then explain to the patient what their role would be in future and hand the patient an information sheet with the contact numbers of the unit. The patient was allowed the freedom to contact the palliative care unit when he/she felt ready for it, but at least an initial contact was made with the patient and the patient was given the contact details of the unit for in case a problem would arise.

## REVIEW PRACTICE

### The last phase of the audit cycle

The last phase of the cycle was completed by reviewing patient referral to the palliative care unit for the three-month period 1 May – 31 July 2002.

In this time 19 patients were diagnosed with cancer. These included colo-rectal cancers (4); prostate cancer (1); Non-Hodgkin's lymphoma (1); metastatic melanoma (3); ovarian cancers (2); cancer of the oesophagus (1); breast cancer (3); bladder (2) and lung cancers (2).



Four patients had previously been referred to the unit and now had recurrent local disease.

Two patients had local disease for which palliative care was not necessary. This leaves 13 patients who could have been referred.

**Table 2:**  
**Summary of potential and actual referrals to the PCU for the period 1 May – 31 July 2002.**

| Patient Number | Time lapse (in days) between diagnosis and referral letter. | Time lapse (in days) between diagnosis and consultation with the PCU | Documented complications                |
|----------------|---|--|---|
| 1              | 10  | 10   |   |
| 2              | 25  | Not seen   |   |
| 3              | 15  | Not seen   | Psychological problems, pain            |
| 4              | 22  | Not seen   |   |
| 5              | 3   | 3  |   |
| 6              | 8   | Not seen   |   |
| 7              | 14  | Not seen   | Dehydration due to feeding difficulties |
| 8              | 8   | Not seen   | Anxiety                                 |
| 9              | 2   | Not seen   |   |
| 10             | 5   | 9  |   |
| 11             | 1   | 1  |   |
| 12             | No letter   | 21   | Nausea and vomiting<br>Admin problems   |
| 13             | No letter   | Not seen   | Advanced disease                        |

Eleven of the thirteen patients were referred the PCU. (8 within the first 14 days of diagnosis). Medical reports for these patients were sent to the PCU. However only 5 of these patients were actually seen by the PCU. Four of the five were seen within 14 days of the diagnosis. Thus only 31% of the referrals met the standard of referral within 14 days of the diagnosis.

The question could be asked whether the non-referred patients' illness did warrant PCU assessment or intervention. From their hospital notes it were evident that these patient did indeed warrant referral. One patient was diagnosed with a metastasis to the brain - an indication of advanced disease; another patient was suffering from depression due to a traumatic previous loss in the family; one patient developed dehydration secondary to therapeutic interventions; and another had administrative problems and came to us without a referral letter.

The reasons for patients not attending the unit were that the patients had been discharged before we received the referral letter. We were therefore unable to see them in the ward. There was also one patient who had requested our involvement, but who did not come to see us.

**Comparison between the initial assessment of practice and the current practice after interventions.**

|   | <b>Before intervention</b> | <b>After intervention</b> |
|---|----------------------------|---------------------------|
| % of patients referred to the PCU by means of a referral letter                                       | 57,5                       | 84,6                      |
| % of patients referred within 14 days   | 42,5                       | 61,5                      |
| % of patients seen by the PCU (including those patients who were not formally referred to the unit) * | 52,5                       | 38,4                      |
| % of patients seen by the PCU within 14 days of diagnosis   | 27,5                       | 30,7                      |

\*Note:

The percentage of patients seen by the PCU before intervention is falsely higher than those seen by the PCU after intervention. The initial assessment was done over a period of six months allowing patients more time to seek assistance, compared to the assessment over a three-month period after the interventions.

## LIMITATIONS TO THE STUDY

1. The biggest limitation was the TIME restraint given the deadline for handing in this thesis. We are still busy implementing the many useful ideas that arose from the interviews.
2. The sample size was very small which limited the power of the qualitative aspect of the study.
3. We were unable to quantify changes that occurred in the attitudes of health care professionals within the hospital. We believe that these were significant.
4. Interviews did not accord with formal qualitative techniques such as free attitude or in-depth interviews. They served a dual purpose exploring barriers to referral by heads of departments as well as giving information about the PCU. They thus formed an intervention as well as a means of data collection and this could interfere with the quality of information gained.
5. Validity of data gained from interviews might have been affected by the interviewer being from the unit that was the subject of the study, and the presence of the tape-recorder.

6. Validity might have been influenced by the interviewer being a colleague of the doctors who were interviewed.

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## **DISCUSSION**

### **Has the set standard of care been met?**

Although 85 percent of patients with cancer (excluding those with local, non-life threatening disease) were referred to the PCU, we realised that the problem was not with lack of referral but that referrals were received by the unit when the patient had already left the hospital.

Patients are still not seen prior to their discharge from the hospital and preventable complications (such as pain, anxiety, and dehydration) still occur, resulting in unnecessary suffering for the patient. Although this was not measured as such, this would impact on the family as well.

It could be asked whether the standard set was not too high, but I think, that all patients with a life-threatening disease should have the opportunity to meet with the palliative care unit, and that the standard should be in fact even higher.

### **Effects of change**

The positive outcome from the study is that awareness of the PCU was increased. A change in some doctors' attitudes was evident, as they even encouraged their colleagues to refer patients with life-threatening disease to the unit. (These were not included in the study as the sample included only patients with a new diagnosis of cancer)

Positive feedback was obtained from other health care disciplines after information sheets were distributed to all the different departments in the hospital. The question was raised whether it would be ethical for health care professionals other than doctors to refer patients to the unit. For example, could the speech therapist responsible for assessing swallowing problems in a cancer patient, refer the patient without the knowledge of the patient's doctor. It (by whom) was decided that the health care professional, as part of the interdisciplinary team and as advocate for the patient, has the responsibility to refer the patient for the best possible treatment, but that he/she still has to refer via the patient's doctor. A recommendation can be made to the doctor for the referral and would hopefully result in the desired referral.

Some of the nursing staff have also started to take on shared responsibility in the care of the cancer patients and informed the palliative care unit of patients who could benefit from palliative care input.

From the interviews it is evident that there are many emotional and personal issues involved regarding referral to the PCU. There is no clear-cut or easy solution to the problem of late referrals. A paradigm shift is needed for all potential role players to see that shared responsibility is required in giving the patient diagnosed with cancer the best possible treatment. This paradigm shift will not take place over night or in such a short time span and our expectations would have been unrealistic if we thought that.

On reflecting on the interviews, a paradox emerged. On the one hand the PCU insists that patients are referred to the unit for holistic care, but on the other hand it also feels that all the doctors should treat their patients holistically themselves. Although attention to the

emotional, social and spiritual well being of patients are especially central to the role of a palliative care unit, they are important in all disciplines.

One of the reasons for insisting on early referral of patients is so that a trusting relationship can be built with the patient over time. Usually trust is only established after you have addressed a problem, usually a physical symptom, for the patient. Once a patient has learned to trust you with the perceived smaller physical needs, he/she will usually open and share their emotional and spiritual needs as well.

The bottom line is that the communication between the referring department and the palliative care unit is lacking. I have the feeling that most of the doctors do not feel negative towards the PCU in particular, but the necessary communication lines are lacking.

Because effective communication is lacking, referral letters reaches the department after the patient has been discharged. Thus resulting in a missed opportunity to meet the patient and his/her family and discussing treatment option plans and other issues.

### **Plans for the future**

The palliative care unit is in the process of negotiating more involvement in the different departments in the hospital. It was decided to attend some of the ward rounds with the different departments, allowing the PCU to meet the patients in the ward as part of the medical team and to emphasise the concept of shared care. So far the reactions from our colleagues were very positive.

The name of the unit was changed from “hospice” to “palliative care unit” so that it is not seen only as a place for terminal care. (We are still awaiting the new signboard to be erected in the ward.)

My colleague and I will put together a short workshop on palliative care, including skills identified as lacking, in the interviews. Representatives from each department could attend this, resulting in better partnership between the different departments, but also raising awareness of doctors own feelings associated with diagnosis of life-threatening disease.

The palliative care unit will submit an article in one of the military journals to raise awareness of the palliative care unit, also within the healthy military population in order for them to understand the different functions of the unit and to support their family members and their friends who are attending the unit.

Permission will be obtained from the military authorities to allow medical students from the local university to rotate in the palliative care unit, allowing them first hand exposure and increase awareness of palliative care.

## RECOMMENDATIONS

The specific recommendations for each barrier to referral were already discussed in the discussion and recommendation section under the different sub-headings and will not be repeated.

1. The audit cycle should be completed again after the implementation of the above mentioned recommendation for the future. Enough time should be allowed for the doctors' attitudes to change, but also for communication to improve.
2. This study included the referral of cancer patients only, but a large part of our work involves patients with HIV/AIDS and also other terminal diseases. The negotiations for the referral of these patients should follow and standards set to improve patient referrals to the palliative care unit regarding these patients as well.

## SUGGESTIONS FOR FUTURE RESEARCH

1. Audits are a useful way of examining and improving practice. Future audits could assess standards of care within the unit. For example one could measure how effectively physical, psychological, spiritual and emotional needs are being met.
2. Comparisons between palliative care units within hospitals compared to those in separate settings could be assessed in order to assess the most effective means of care.
3. Guidelines, based on input from various disciplines, for the palliative care of patients with AIDS need to be established.
4. Interventions to help students and doctors to face their own mortality and sense of helplessness in the face of terminal illness need to be devised and assessed in order to overcome barriers to care.

## CONCLUSION

The power of this study to show a significant increase in referral rates was limited by a small sample size. The qualitative part of this audit has clarified some of the barriers to referral by doctors. Intervention in the form of interviews and the giving of information has promoted communication between the PCU and other departments in the hospital.

Life-threatening disease can be experienced positively by both the patient and the family members, as it can allow time for healing in another dimensions of the person.

As Bennett <sup>17</sup> remarked *“Sometimes one can clearly see a patient who appears to be undergoing growth and development in a dimension that can not be measured scientifically. A dimension that can only be called ‘spiritual’. It appears that as the needs for the body and mind become less insistent, the needs of the spirit becomes dominant. When one has had the privilege of watching someone achieve perfect serenity and acceptance, one always hopes for this to be achieved by all”*

## ACKNOWLEDGEMENTS

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## 2 MILITARY HOSPITAL



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## PALLIATIVE CARE UNIT

We at the palliative care unit (previously known as the HOSPICE) are trying to improve referrals to our unit. We realized that referring doctors were not always sure whom to refer or when to refer them. We hope that this short note will share some information regarding our unit.

### AIMS

- To ensure good follow-up of all cancer cases (both curative and palliative cases)
- To provide palliative care for incurable disease
- To render assistance by the multidisciplinary team when it is required
- To keep the National Cancer Register up to date

### WHO TO REFER

All oncology patients who require further treatment e.g. chemotherapy and/or radiotherapy, and attend outside hospitals for treatment. This is to ensure that the necessary authority to (DD63) and regular feedback from the different oncology departments are obtained. An oncology record for each patient is kept in the unit and records from outside hospitals are kept up to date as far as possible. All incurable oncology patients must be referred for palliative care.

### WHEN TO REFER:

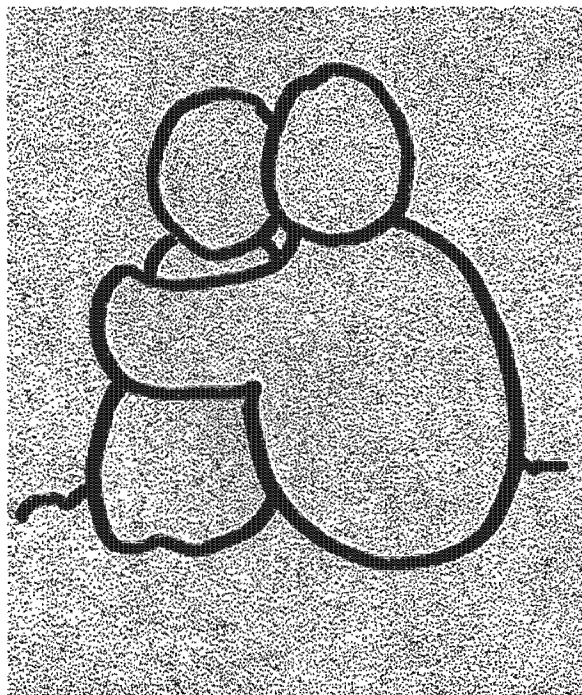
As soon as the diagnosis are made either hystologically or cytologically. Preferably if the patient is still in the ward, before discharge. One of the palliative care doctors will come to see the patient in the ward. If the patient is seen in an outpatient clinic, please ask the patient to make an appointment to meet us. He/she can come to the unit to collect an information sheet before returning home.

### HOW TO REFER

Please complete one of the green/yellow "oncology cards". It should be available in all the departments and clinics. If you need to refer urgently, you are welcome to phone us. We will try to see the patient immediately or at least on the same day.

PS. Information sheets will follow in future regarding patients with diagnosis other than cancer.

## 2 MILITARY HOSPITAL



## PALLIATIVE CARE UNIT

You have recently been diagnosed with cancer and may still feel shocked about this. This is a normal reaction.

Your doctor has referred you to the "palliative care unit" and you no doubt wonder what this means?

Palliative Care is not just terminal or Hospice care. When an illness can no longer be cured, palliative care ensures that all your needs are addressed. Our aim is to help you live as well, comfortably and productively as possible.

Our unit is unique in that we also provide holistic care to patients whose cancer can be cured.

At 2 Military Hospital our aim is to:

### Ensure continuity of care:

Patients are often uncertain of where to go with a problem. They might have a worrying symptom, but are scared that they will be a "bother" to the busy physician or surgeon. This is exactly the reason why we are here - to address those worrying symptoms. We feel that each patient needs a specific team that will oversee his/her care.

### Take responsibility for administrative duties:

2 Military Hospital does not have a specialist oncology unit. This implies that patients are referred to outside facilities like Groote Schuur and Tygerberg Hospital.

With each visit to an outside hospital or specialist, you will require an authority letter (DD63) from 2 Military Hospital.

This can be arranged by us, by contacting the ward secretary or any one of the doctors in our unit prior to your visit.

Remind your oncologist to give you written feedback of your visit to enable us to update your 2 Military folder.

We will also be responsible for the authorization of your chemo and/or radiotherapy. Each patient's treatment has to be authorized by HQ in Pretoria.

As soon as your treatment has been approved, the pharmacist at 2 Military Hospital will order it just for you.

He/she will send it to Groote Schuur or Tygerberg hospital, where the oncology unit will administer the drugs.

### Co-ordinating the functions of an interdisciplinary team:

We are privileged to have access to an interdisciplinary team.

The team consists of 2 full time doctors, a psychologist, a social worker, chaplains, physio - and occupational therapists, a speech therapist, a dietician, dedicated nursing staff and a committed ward secretary.

You will not necessarily see all of these disciplines. Your specific needs will dictate which of the members you will see.

### For example:

Sometimes cancer treatment can temporarily impair your ability to swallow, or you can lose your appetite. You might have special feeding requirements. We will bring you in contact with our dietician who will address these problems.

### Other functions:

We will also be responsible for the ordering of prosthesis and wigs, should it be necessary. Please contact the ward secretary so that she can give you the necessary information.

Some questions you might ask:

1. Am I now written off by my doctor?

Definitely not!!!

We will be responsible for your future oncology follow-up, but this does not mean that the rest of the hospital is "off - limits" to you.

If a problem arises that requires specialist input from any other department, you will be referred to the appropriate department.

2. What if I choose not to attend the palliative care facility?

You are free to seek the help of another doctor. Just keep in mind that it is easier to co-ordinate treatments from a central point.

As the doctors at Groote Schuur and Tygerberg hospital are aware of our facility, they often communicate their concerns and advise our unit.

We are trained in palliative care medicine, and probably do know a little more about oncology symptoms and disease management than the average general practitioner.

3. Why can the drugs not be administered at 2 MH?

Chemotherapy drugs are very toxic and have to be given in very precise dosages by specially trained staff, who have the knowledge to foresee and treat drug reactions.

We hope we can be of service to you and are looking forward meeting you.

You can contact us at the numbers on the front page, or pop in our ward on the second floor.

Dr. M. Engelbrecht  
Dr. M. v/d Berg

University of Cape Town