

**Difference in quality of life of referred hospital patients
after hospital palliative care team intervention.**

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**A research report to the Faculty of Health Sciences,
University of Cape Town, in partial fulfillment of
the requirements for the degree of
Masters of Palliative Medicine.**

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Declaration

I declare that the research report entitled "Difference in quality of life of referred hospital patients after hospital palliative care team intervention" presented for the degree of Masters of Palliative Medicine at the University of Cape Town, is my own unaided work, and has not been presented for any degree or examination at any other university.

Signed:

Signed by candidate

This.....12th.....day of...Nov....2004

ABSTRACT

Since 1948, when the World Health Organization (WHO) defined health as being not only the absence of disease and infirmity but also the presence of physical, mental, and social well-being (Constitution of the World Health Organization, 1952), quality of life issues became more apparent. The aim of the research undertaken was to establish whether the hospital palliative care team (HPCT) at the Johannesburg General Hospital was making a difference to referred hospital patients' quality of life. The HPCT was started at the Johannesburg General Hospital in 2001. The team functions as an advisory body on pain and symptom control. Palliative Care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. The method used was the FACT G questionnaire, which was completed by the patient group initially, and thereafter HPCT intervention. The questionnaire is used to measure quality of life (QOL). The study is a descriptive cohort design. The first 24 patients completed the informed consent prior to completing the questionnaire. The pre QOL questionnaire served as the baseline QOL scores prior to HPCT intervention. The initial QOL scores were then compared to the post QOL scores after HPCT intervention. Seven subjects were excluded from the research as six patients were discharged from hospital early due to a bed shortage and one patient died. The seven patients' results from the pre FACT G questionnaire were discarded and all subsequent calculations did not include their results. The increase in the total percentage scores (45.53 to 63.35) was statistically significant ($p < 0.001$) using the paired t-test. Thus the results show a significant difference between pre and post assessment QOL scores. The research demonstrates significant improvements in patients' quality of life ($p < 0.001$) after HPCT intervention. It is hoped that future research would continue to show the value of HPCT and their effect of benefiting patients' quality of life.

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LIST OF ABBREVIATIONS

AIDS	Acquired immune deficiency syndrome
CEO	Chief executive officer
HBC	Home-based care
HIV	Human immunodeficiency virus
HPCT	Hospital palliative care team
NGO	Non governmental organization
NHS	National health system
PMI	Palliative Medicine Institute
QOL	Quality of life
US	United States
USA	United States of America
WHO	World Health Organization

KEY TERMS USED IN THE RESEARCH

Palliative Medicine is defined as supplying the medical and nursing needs for patients and their families with the aim of relieving suffering. It addresses not only pain and symptoms, but also emotional, psychosocial and spiritual suffering.

Palliative Medicine developed out of the Hospice movement (terminal care facility) and was therefore defined by WHO (Technical Report series 804; 1990) as being relevant for those for whom cure is no longer possible.

Professor Browde/PMI created an *expanded* definition, which is as follows-

‘Palliative Care supplies active comprehensive care for the physical, emotional, psychosocial and spiritual suffering of the patient and the family.

It starts at the moment of first contact with the patient with any illness at any stage and continues for the duration of the illness. If and when the illness becomes incurable, Palliative Care then plays the major or total role’ (Browde, 2001).

WHO revised Definition of Palliative Care (2002)-

Palliative Care is an approach that improves the quality of life of patients and their families facing the problems associated with life- threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative Care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient’s illness and in their own bereavement

- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated
- will enhance the quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (Sepulveda et al, 2002).

The above definitions are those applied in this research.

CHAPTER ONE

INTRODUCTION

BACKGROUND TO THE PROBLEM

QUALITY OF LIFE

Since 1948, when the World Health Organization (WHO) defined (health) as being not only the absence of disease and infirmity but also the presence of physical, mental, and social well-being (Constitution of the WHO, 1952), quality of life (QOL) issues became more apparent. Ware (1984) views QOL in the broader context of a patient's immediate and more distant environment. The impact of a disease on quality of life is structured much like the concentric surface ripples seen after dropping a stone in the water. Initially, the effect is on the patient's physiology; this then spreads to physical functioning, psychological functioning, general health perception, and, finally, social role functioning (Doyle, 1998:84). Calman (1984) defined QOL as the difference between a person's ideal state and their actual state. The intention in QOL is to try and narrow the gap between the two (Ahmedzai, 1999).

THE HOSPITAL PALLIATIVE CARE TEAM

The hospital palliative care team (HPCT) based at the Johannesburg General Hospital undertook the research. The hospital is a government tertiary level care facility situated in Gauteng, South Africa. The HPCT was started at the Johannesburg General Hospital in 2001. It was initiated by Professor Browde of Palliative Medicine Institute (PMI) a non-governmental organization (NGO). The team functions as an advisory body on pain and symptom control. The aim is to try and assist in alleviating patients' suffering. The suffering may be caused by a physical problem (for instance a painful hip, vomiting, constipation), together with emotional, psychosocial and/or spiritual issues; in so relieving the suffering there is an improvement in the patient's QOL. Two Palliative Care trained professional nurses and two part-time doctors currently staff the team. The team is

run under the auspices of “nurse- run, doctor- directed” framework meaning that the nurses review all the patients and direct the doctor/s to the difficult cases in need of urgent review. I am one of the part-time doctors, co-ordinator of the team as well as the researcher of the HPCT.

FUNCTIONS OF THE TEAM

The team serves a wide community covering the following hospital wards- surgery, medicine, oncology and the specialist units. The team currently receives referrals for any *physical* problem for example pain that the ward medical staff may be finding difficult to control (as per key terms). Referrals are received from all of the above adult wards as well as out- patient clinics via telephonic or written requests. A paediatric service is currently not provided by the team. A monthly average of 160 patient reviews are conducted in the wards as well as the clinics.

The team assists at Virology clinic on Friday mornings, which is an out- patient clinic for HIV positive patients. This clinic is one of the South African National rollout programme sites, which are pilot sites, identified as the initial areas to start providing anti-retroviral drugs to the public. The clinic staff conducts patient consultations assessing their current state of health and whether they require anti-retroviral drugs. The patients have to have a minimum of three compliance visits plus a CD4 count of below 200 (HIV marker) to be eligible for this clinic. Any patient who does not meet these requirements is referred to their closest local clinic for follow up care.

The team acts as a link between the government hospital and outside community services for example hospices and home based care (HBC). HBC is the cornerstone of Palliative Care; it aims to be compassionate, patient- centred and empowering families to care for the patient at home. Short- stay admission for control of symptoms or family respite may be required. The aim is to discharge the patient to the HBC programme when the condition is controlled (Wilson et al, 2002). HBC provides carers to visit the patient and family at home to supervise for instance wound care, medication and when to seek medical care. Referrals to community services are made on behalf of the patients when

they are not coping with care at home, or in cases where patients are either not ready to go home alone or are destitute. The facility required, for instance HBC, would depend on the patient's request, current state of health and availability of this resource in their residential area. The HPCT nurses thus form a linkage with the community staff in these facilities and advocate on behalf of the patient and their family.

Counseling is a large part of the HPCT role, referrals for *emotional* issues are dealt with in the form of one on one sessions informally in the ward as well as support group workshops. Trained staff, volunteers and our nurses at the HIV clinic, facilitates these group workshops. Information delivery for patients needs to be individualized with particular attention to process at all stages of illness. Patients and families use secondary sources of information to complement and verify information given by health carers (Kirk et al, 2004).

Palliative Care promotes an ethos in the doctor/nurse/patient relationship, which is patient-orientated and not disease-orientated; it requires non-judgmental attitudes in a multidisciplinary team approach (Browde, 2001). The team has links with the hospital social workers, which aid our team in the *social* issues of our patients for example disability grants. Another vital function is *spiritual* care of our patients, which is aided by our links with the pastoral support available at the hospital. Currently two volunteer members head up the pastoral team. Spiritual needs change with time and circumstances. The National Institute for Clinical Excellence guidance, Supportive and Palliative Care for Adults with Cancer, published in March 2004, acknowledges this and recommends that healthcare teams ensure accurate and timely evaluation of spiritual issues through regular assessment. This reflects the increasing emphasis on spirituality as a factor contributing to well-being and coping strategies (Pargament et al, 2000; Walsh et al, 2002; McClain et al, 2003; McIllmurray et al, 2003).

It had long been recognized that if the philosophy of Palliative Care is to be of benefit to the majority, then that philosophy must be embraced by teaching (O'Neill et al, 1992).

The ongoing education of ward staff on Palliative Medicine is another vital function of the team. Education occurs informally in the wards as well as in-service training. This service is provided on the request of the medical ward staff.

1.1 RATIONALE FOR THE RESEARCH

The question asked by this research was whether the hospital palliative care team (HPCT) was making a difference to referred hospital patients' quality of life. No systematic evaluation has been carried out since the HPCT was established in 2001. It is thus very difficult to motivate for example for the need for expansion of our team, teams in other facilities or funding. I considered doing the research so that it could enable us to evaluate our service, with the long- term vision of broadening our base of services to more patient communities and hospitals. Evaluation is vital for comprehensive patient care and accordingly I was motivated to do the research. Audit is now a mandatory activity for accreditation for training of HPCT units in the United Kingdom (McCarthy et al, 1991; O'Neill et al, 1992). In South Africa we have very few HPCTs, another important factor for me conducting this research. Research and education will become increasingly important if services within hospitals are to survive (O'Neill et al, 1992; Manfredi et al, 2000; Smith et al, 2003; Rabow et al, 2004), as is the situation in South Africa.

It has been established by these research findings that the HPCT at the Johannesburg General Hospital offers good Palliative Care, which up to now had not been assessed. This is vital as early studies suggest that good Palliative Care can improve the identification and treatment of symptom distress, promote doctor-patient communication, streamline medical decision making, and organize safe and effective care in the community (Manfredi et al, 2000; Rabow et al, 2004). Data also suggest that Palliative Care programs in hospitals reduce utilization and costs, perhaps by helping patients make medical decisions concordant with their goals and by supporting continuity of quality

medical care after a hospital stay (Smith et al, 2003). These programs have grown rapidly in hospitals in recent years, numbering over 950 in the 2002 American Hospital Association annual survey, an increase of 45% from 2000, unlike most other countries. Many Europeans who are terminally ill die in unnecessary pain and discomfort because their health systems lack skilled staff and do not widely offer Palliative Care services, according to two studies published by the World Health Organization this month. In the two reports WHO found that although Europe's population is ageing and more people are dying of chronic diseases, the range and quality of Palliative Care services remain severely limited and inadequate (Desbiens et al, 1997; Fleck, 2004). HPCTs as well as Palliative Care services are extremely scarce in South Africa. A consortium of national Palliative Care organizations recently completed a consensus document on guidelines for best practices for Palliative Care programs in health care institutions, precisely to promote the kind of quality, consistency, and reduction in variability in care practices that Wennberg et al's study (2004) calls for.

While medical advances have transformed many illnesses that once proved rapidly fatal into chronic conditions, improving the quality of this resulting longer life has been more difficult to achieve (Somogyi-Zalud et al, 2000). The right to a good death should be fundamental stated David Hinchliffe, chairman of the House of Commons Health committee, choices are not being realised for those who are terminally ill (Kmietowicz, 2004). WHO said that many patients who are dying need support from their relatives and health workers to help them cope with disability, pain, anxiety, and depression, while relatives of the patients also need help to cope with their own anxiety and depression (Fleck, 2004). The research data could therefore be helpful in furthering our HPCT structure to reach more patients' and improve their quality of life via HPCT intervention. There is a sense of urgency in developing a service co-ordinated by nursing, in collaboration with the multi- disciplinary team, which will meet the current needs of the people (Skilbeck et al, 1997).

1.2 AIMS AND OBJECTIVES

The aim was to evaluate the effectiveness of the HPCT at the Johannesburg General Hospital.

Objectives:

- 1.2.1 To establish the baseline QOL of referred hospital patients prior to HPCT intervention.
- 1.2.2 To establish the changes in QOL of these hospital patients after HPCT intervention.

The objectives were achieved using a QOL questionnaire completed by the patient before and after HPCT intervention.

CHAPTER TWO

LITERATURE REVIEW

The literature review was undertaken using Cochrane data bases together with journal, internet and library book articles. I was able to find minimal literature pertaining directly to our South African services and hospital situations. It was noted that there is very limited literature about hospital teams and their workings at an international level. There is even less information available on the functioning or teamwork component of HPCTs (Hill, 1998). Despite their contribution to the care of the dying over the last 10 years, most published research concentrates on either the symptom aspect of work, audit, or the financial aspects of care provision (Higginson et al, 1990; 1992). I have therefore included a general literature review on hospital care and quality of life, highlighting relevant aspects for my research. In view of the gap in the literature, especially locally, the value of this research pertaining to our South African setting is underlined.

2.1 HOSPITAL SERVICES

A study done in highly respected USA hospitals nationwide by Wennberg and colleagues' found that the improved management of chronic illness and end of life care are priorities and should be determined by patients' needs 'and not the capacity of the acute care system' (Wennberg et al, 2004). Data from the recent Study to Understand Prognoses and preferences for Outcomes and Risks of Treatment (SUPPORT) indicate that the care of hospitalized dying patients continues to be inadequate in USA (Miller et al, 1996:1740). The effective management of chronic illness needs integration across the entire spectrum of care, of which acute care is but one component and perhaps not the most critical. The findings reported by Wennberg et al (2004) prompted concerns amongst the English whether the English NHS Plan and its commitment to providing 9500 more doctors and increasing bed capacity by 7000 beds would be entirely wise or appropriate if having more of them doing the same sort of work in the same way is no guarantee of better healthcare (Department of Health, 2000; Leathermann et al, 2003).

There is other solid evidence that the care of the seriously ill and dying needs improvement in US hospitals. Multiple studies have demonstrated high levels of pain, other symptom distress, poor doctor-patient communication about the goals of care and the medical decision making that should follow, and burdens on family care-givers (SUPPORT, 1994). Palliative Care is medical care focused on relief of suffering for those with serious and advanced illnesses, support for doctor-patient communication, and delivery of coordinated, continuous, and comprehensive medical care for patients and their families (Billings, 1998; Manfredi et al, 2000; Von Gunten, 2002; Rabow et al, 2004). WHO called on health policy makers to urgently address the needs of ageing populations and to make Palliative Care a core part of their healthcare services as early identification of pain and other health problems can make a dramatic difference.

Dr. Tsouros, head of the Centre for Urban Health at WHO's European regional office stated that Palliative Care is by and large a neglected topic in most countries and what is required is both a social and a political impetus. (Fleck, 2004). It is thus hoped that if Palliative Care were integrated in all hospital services then this suffering would be avoided. The prevention and relief of suffering caused by human sickness should be the fundamental goal of medicine according to Cassell (2004).

Patients with cancer should have access to a range of services from the moment their cancer is diagnosed to help them cope with their illness and its treatment, say recommendations from the National Institute for Clinical Excellence (NICE) in England and Wales. Supportive care and information services for people and their families should be developed by health planners with the same priority and detail as diagnostic and treatment services, say new guidelines for England and Wales. They should receive important news from senior staff that have been trained in effective communication, and they should have access to a key worker, if appropriate, to act as a guide to the services offered by each cancer network. As well as high quality written information about cancer and treatments, patients should be assessed at critical stages through their illness and have access to counselling services to help deal with any anxieties (Kmietowicz, 2004). This applies to patients with other illnesses as well, for example HIV. At the turn of the

century, Africa contributed over 70% to the global burden of people living with HIV and acquired immune deficiency syndrome (AIDS). In the absence of successful prevention efforts, AIDS-related deaths are expected to rise from around 225 000 in 2001 to a plateau of around 630 000 per annum in 2012 (Wilson et al, 2002). This currently significantly affects our HPCT patient load with over half of our patients being HIV positive.

2.2 HOSPITAL PALLIATIVE CARE TEAMS

Despite a national network of hospices, the majority of patients continue to die either at home or in an acute hospital setting (North East Thames Regional Health Authority 1992). This has led to the development of specialist hospital palliative care teams (Hill, 1998). One of the most interesting and important developments in the provision of specialist Palliative Care in recent years has been the emergence of hospital palliative care teams at an international level (Dunlop et al, 1990). The development of the teams and their work patterns has been influenced not only by new insights in hospice care and in pain and symptom control but also by financial constraints (O'Neill et al, 1992; Smith et al, 2003). Palliative Care services deliver direct patient care and also have an advisory and educational role to influence the quality of care in the community and in hospitals (Ellershaw et al, 2003). Specialist Palliative Care can be provided in the inpatient units and in the patient's home and the benefits of such an advisory team can scarcely be overstated. The costs are almost entirely salaries (Doyle, 1998). There is indirect evidence that the HPCTs service may contribute to cost savings for the parent institutions by improving pain and other symptoms, reducing inpatient length of stay, avoiding unnecessary investigations, and facilitating care either at home or in alternative institutions or hospices (O'Neill et al, 1992).

Palliative Care also provides a parallel support system to help families cope during the patient's illness and in bereavement, which is best provided by a multiprofessional team (Twycross et al, 2003). In theory, a multiprofessional team harnesses the skills required for the task and combines them in a unique way, which is impossible outside the team (Ovretveit, 1995; Kite et al, 1999). This has a number of advantages, which include an

increased range of services; the workload is easier to manage for ward staff, collegiate support, cross-fertilization of ideas and a more holistic approach. Palliative Care teams usually include members from nursing, medicine, social work, pharmacy, pastoral service, nutrition, physiotherapy, occupational therapy, and home care. Volunteers may also work with the team to bring diversion, support and friendship to patients and their families. The depth of involvement of each team member will vary with each situation. Where no formal team exists, the physician can gather a team of relevant professionals who will be involved (Skilbeck et al, 1997; Latimer, 1998:25). Such teams strive to improve their patients' QOL.

2.3 QUALITY OF LIFE

Quality-of-life issues have become steadily more important in health care practice and research. There has been a nearly exponential increase in the use of all forms of QOL evaluation as a technique of clinical research since 1973 in the USA (Bucholz et al, 1996; Testa et al, 1996). The effects of medical treatments and programs on QOL should not be ignored simply because such effects are difficult to measure (Testa et al, 1992). Factors contributing to QOL include psychological state, physical function, social relationships and social roles (Calman, 1984; Colbourne, 1995; Doyle, 1998). There is a great need to promote and enable more Palliative Care so that all patients will achieve best possible quality of life (Cassel et al, 1996; Doyle, 1998; Manfredi et al, 2000; Browde, 2001; Smith et al, 2003; Rabow et al, 2004). Gauteng Health Department highlighted in their document on Palliative Care that the most important factor of HIV patients is their quality of life (Gauteng Health Department, 2001). The data plus sharply rising costs of medical care for people living with chronic conditions have led to a more intensive focus on improving care quality at the bedside with the goal of delivering the right care to the right patient at the right time and place (Emanuel et al, 1994; Meier, 2004). Improving the care of the seriously ill, the same population whose care is described in Wennberg et al's study (2004) is the primary mission of the burgeoning palliative care movement in the US, which was conducted in academic health centers to Medicare patients in US.

With the integration of life-sustaining treatment and Palliative Care, it is important to address the idea that many clinicians, patients, and family members continue to hold: that forgoing life-sustaining treatment means 'giving up' and 'doing nothing' for the patient (Sachs et al 1995; Teno et al, 2004). Alison Richardson, professor of cancer and palliative nursing care and leader of the guidance development team, stated that anyone who has experienced cancer would understand the importance of supportive and Palliative Care provided by a very wide range of health and social care professionals. The evidence shows that in addition to receiving the best treatments for their cancer, patients want to be treated as individuals, with dignity and respect, and to have their voices heard in decisions about treatment and care (Kmietowicz, 2004). The manner in which patients' emotional distress is handled in the initial stage of diagnosis can have a long-term effect on the entire treatment and adjustment process (Gauteng Health Department, 2001).

The formation of HPCTs is a recent development in Palliative Care and little is known about how they function. The small study by Hill (1998) offers an insight into the views of a mixed group of professionals working in Greater London. Hill states that this would assist teams to function more effectively, and provide a better understanding of the specific issues experienced in an especially stressful area of health care, where effective team functioning is essential to ensure optimum use of scarce resources (Hill, 1998:221). The data collected are context dependent and further research is necessary to clarify issues involved in HPCTs.

CHAPTER THREE

MATERIALS AND METHODS

3.1 PREPARATION FOR RESEARCH

Permission to conduct the dissertation research as part of a postgraduate programme in Public Health study was obtained by the Ethics Committee of University of Cape Town. The study took place at the Johannesburg General Hospital by the hospital palliative care team members. The CEO of the hospital Mr. Manning gave us permission to conduct the research. The team members were informed verbally of the research we were to conduct on our ward rounds. The patients' were invited to join the research study; the aim of the research was explained and how significant the need for audit of our team was. The need to obtain informed consent from each patient prior to completing the questionnaire was explained. The patient had every right to refuse exclusion from the study, which would in no way jeopardize their further care. The referred patients seen on our ward rounds were asked to participate and if in agreement the consent form completed. Each patient was made aware that a follow-up/after HPCT intervention questionnaire would be requested. The questionnaire was either completed independently by the patient or in an interview format depending on the patient's request. The team supervised the questionnaires. Dr. David Cella, a professor of psychiatry and behavioural science at the Northwestern University, Evanston, compiled the FACT G questionnaire. I obtained permission from him to use his questionnaire in my research.

3.2 RESEARCH DESIGN

The study is a descriptive cohort design. It has one patient group completing both pre and post HPCT intervention QOL questionnaire. The independent variable is the HPCT intervention whilst the dependent variable is the outcome as measured by the QOL questionnaire. The time interval between pre and post measurement was variable ranging from days to months dependent on the patient's condition and reason for hospitalization. A decision to not have a control group was taken, the reason for this was that the study used a within study design in which a group of individuals is measured, then subjected to an intervention, and then measured again (Hicks, 1995). The purpose of this research was to observe the effect of the HPCT intervention on QOL. The pre QOL questionnaire in the research served as the baseline QOL scores prior to HPCT intervention. The initial QOL scores were then compared to the post QOL scores after HPCT intervention.

3.3 SUBJECTS

The first 24 patients referred to the HPCT who consented to completing the QOL questionnaire were included in the research, forming an availability sample of non-probability type. The 24 patients signed the informed consent form [Appendix A] prior to completing the questionnaire. A period of four months was required to identify 24 patients who signed consent. Seven subjects were excluded from the research as six patients were discharged from hospital early due to a bed shortage before the follow up questionnaire could be administered and one patient died. The seven patients' results from the pre FACT G questionnaire were discarded. Nil patients refused permission to participate in the research. The only exclusion criterion was patients whom were unconscious and thus unable to give consent. It was explained to the patients that participation in the research would in no way jeopardize their treatment should they decide to withdraw.

3.4 METHODS

3.4.1 THE FACT G QUESTIONNAIRE

On the day that the patients' were accepted into the research, after completion of the informed consent form, they were given the FACT G questionnaire (Version 4) to fill in (Appendix B). It measures QOL of the individual, covering four sections- physical, social/family well-being, emotional, aswell as functional well-being. The questionnaire is psychometrically sound, a core instrument and available in many languages as per Dr Cella information sheet. We had translations of Tswana, Zulu and Pedi / Northern Sotho available. The FACT G was designed for patient self-administration, but can also be administered by interview format. Confidentiality was ensured by assigning a number to each pair of questionnaires completed so that I knew which pairs correlated without patient names (e.g. 1A= pre intervention questionnaire and 1B= post intervention questionnaire of same patient). The information was then recorded in a book for each patient. The same procedure/ process was conducted for post intervention questionnaire.

3.4.2 STATISTICAL ANALYSIS

The scores were worked out manually using the FACT G scoring guidelines (Appendix C).

The data were kindly analysed by the Statistics Department at the University of Cape Town. The statistics package was Stata version 8.

The statistical package used was :

StatCorp. 2003. Stata Statistical Software: Release 8.0. College Station, TX: Stata Corporation

The data were found to be symmetrical and thus the paired t-test was used comparing favourable versus unfavourable outcomes of QOL.

CHAPTER FOUR

RESULTS

Here within is the demographic data as well as the pre and post intervention scores obtained from FACT G questionnaire.

4.1 DEMOGRAPHIC DATA

The gender and age of the patients are shown in table 4.1

TABLE 4.1 Gender and age data

Results:

GENDER	Freq.	Percent
F	13	54.17
M	11	45.83
Total	24	100.00

	AGE (years)
Number:	24
Mean:	52.3
Median:	51
Standard deviation:	13.5
Range:	26 - 77

Seven subjects were excluded from the research as six patients were discharged from hospital early due to a bed shortage before the follow up questionnaire could be administered and one patient died. The seven patients' results from the pre FACT G

questionnaire were discarded and all subsequent calculations did not include their results. As seen from Table 4.1 the mean age of the subjects was 52.3 years.

4.2 THE PRE FACT G SCORES VERSUS THE POST SCORES

All seventeen subjects completed the FACT G questionnaires before and after HPCT intervention. The results were calculated as a total percentage score with the following four sections making up the total:

Physical well-being	score range 0-28
Social/family well-being	score range 0-28
Emotional well-being	score range 0-24
Functional well-being	score range 0-28

The total FACT G score range being 0-108, which was then converted to percentage score (Appendix C). The results showed an improvement of the total score percentages in QOL after intervention ($p < 0.001$).

The individual section scores of all the questionnaires added together are listed below:

PRE HPCT INTERVENTION:

Physical well-being	Total score 147
Social/family well-being	305
Emotional well-being	204
Functional well-being	181

POST HPCT INTERVENTION:

Physical well-being	Total score 295
Social/family well-being	331
Emotional well-being	270
Functional well-being	285

From the above results we can see that all individual sections of the FACT G questionnaire improved after HPCT intervention, the highest score being *physical well-being*, for example patient's energy, nausea and pain. The pre-score was the lowest in this category. The other large improvement was in *functional well-being*, which also was relatively low on pre-score. The least difference observed is in *social/family well-being*.

The total percentage scores for each questionnaire were used in the analysis. Table 4.2 and graph 4.3 reports the percentage scores obtained for FACT G questionnaire both pre and post HPCT intervention. An increase in the FACT G percentage total scores indicates an improvement in quality of life. The results are presented in Table 4.2

The paired t-test was applied to compare differences between pre and post percentage scores.

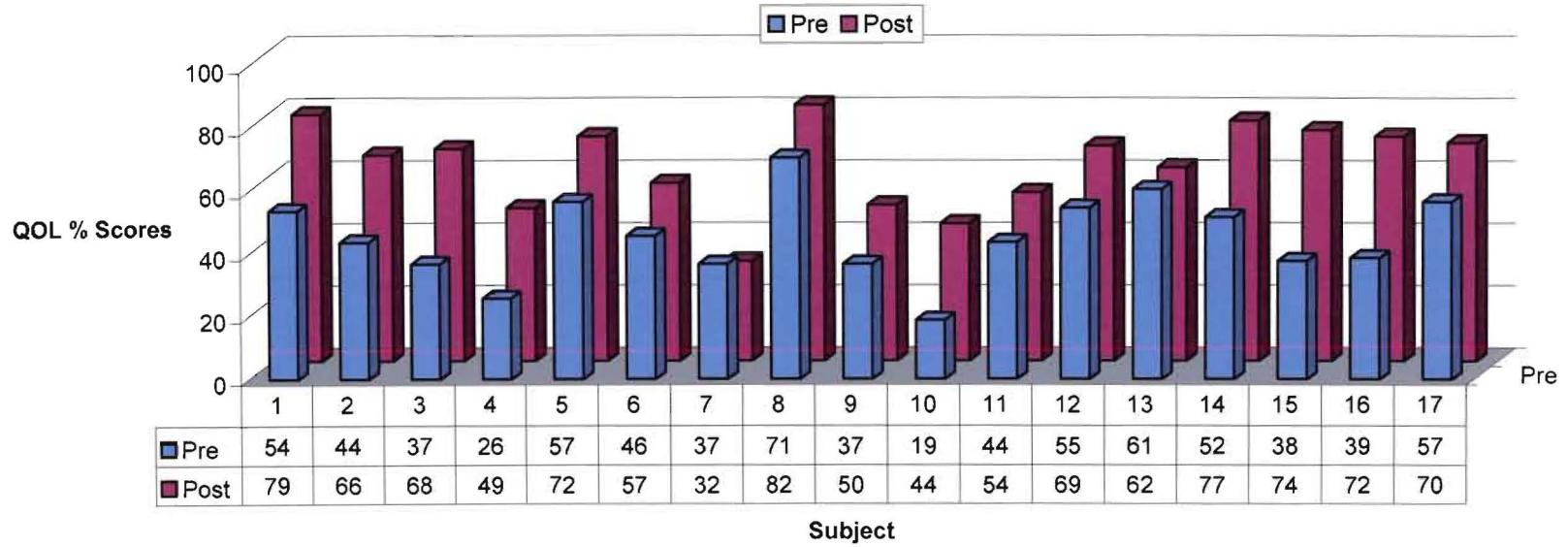
TABLE 4.2 Pre and post intervention percentage scores obtained from FACT G questionnaire

Assessment	Number	Mean	Standard deviation
Post-score	17	63.35	13.73
Pre-score	17	45.53	13.14
Difference		17.82	

Paired t-test: $t=6.64$; $P<0.001$

The increase in the total percentage scores (45.53 to 63.35) is statistically significant ($p < 0.001$) using the paired t-test. Thus the results show a significant difference between pre and post assessment QOL scores. We can therefore conclude that the HPCT interventions are creating a positive contribution to the hospital patients' QOL based on these results.

Graph 4.3



CHAPTER FIVE

DISCUSSION

An intervention study measuring the QOL of referred hospital patients prior to HPCT intervention and thereafter was outlined. The instrument used was the FACT G questionnaire, designed as a self-administered questionnaire, consisting of four main sections including physical, social/ family, emotional and functional well-being. In order for a quality of life questionnaire to be useful in the clinical trial setting, it should demonstrate an ability to detect changes over time due to new therapies. It should also detect differences among relatively small groups (Wood, 2001). The questionnaire has face validity for our South African setting and thus I had the questionnaire translated into Tswana, Pedi/ Northern Sotho and Zulu. The questionnaire was found to be both practical and an easily administered one as our patients managed to complete it with very few further questions, the sentences used were short, concise and the patients readily recognized the relevance to their situation and conditions.

5.1 LIMITATIONS

5.1.1 INSTRUMENTATION

The Fact G questionnaire has been standardized in the United States but not in a South African population.

5.1.2 LACK OF CONTROL GROUP

A reason for not including a control group was mentioned in the Materials and Methods section. The team's ethical standards precluded the withholding of intervention for the purpose of experimental control. It is difficult to measure the effectiveness and success of a palliative care team, as explained below- success in the control of symptoms and the resolution of psychosocial problems could be measured, but comparisons could not then be made with a comparable group of patients. An option may have been to conduct a control group using patients from a hospital which does not have a HPCT.

5.1.3 INTERVENTION VARIABLES NOT CONTROLLED

There are many intra-individual, day-to-day variations among the patients measured, for instance mood, staff members, sleep and physical state. Staff members include all those working in the ward from the floor cleaner to the charge nurse. The better the staffs' quality of care of the patients the greater their recovery. As the staff work on shift rotations, this allows for large variations of patient care. Mood for example is subjective and may have affected the results. The major problem is ascribing the change in measurements to the intervention since other factors may also have changed that interval. It is therefore possible that confounding factors such as a change in ward staff may affect the results.

5.1.4 BIAS IN MEASUREMENT

A team member who had been involved in the intervention supervised the completion of the questionnaire. Reflexivity on the part of the patient could have increased the post-score.

5.1.5 HAWTHORNE PHENOMENON

The members of the HPCT were aware of the research being conducted and were thus very motivated to administer questionnaires and await the results, which they hoped would be positive. It is possible that their work, as the independent variable, was positively influenced.

5.2 RECOMMENDATIONS

A.] The continuation of the HPCT because of the useful role we hold within the hospital, by assisting in the improvement of patients' QOL, thus proved within this research.

B.] Future research of more hospital patients using the FACT G questionnaire in evaluating interventions that may have a positive effect on quality of life. The ease of administration and the use of items that address relevant concerns without reference to specific treatment strategies make the FACT G questionnaire applicable to a diverse group of patients. It is hoped that future research would continue to show the value of HPCT and their effect of benefiting patients' quality of life.

C.] Future studies could be done with follow up questionnaires being completed after patients' discharged to see if QOL values further improved over an extended period and in a different environment.

D.] The HPCT provides a pilot team model for further development of the required basic structure of a team for the delivery of effective Palliative Care in hospitals without these services.

E.] The implementation of HPCTs into all major local hospitals with further infiltration into smaller hospitals over time.

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APPENDIX

7.1 Appendix A:

Informed consent form in English/Zulu/Sotho

7.2 Appendix B:

FACT G questionnaire in English

Tswana, Pedi/ Northern Sotho and Zulu available.

7.3 Appendix C:

FACT G scoring guidelines

7.1 Appendix A:

Informed consent form in English/Zulu/Sotho

INFORMED CONSENT FORM.**Please note that the questionnaire we are requesting you to fill in is entirely voluntary**

[i.e you have the right to refuse to complete it] If you refuse to complete it or withdraw at any time there will be no prejudice to quality of your care.

The questionnaire will be requested to be filled in before HPCT intervention and thereafter [i.e. two separate occasions]

Your help will be gratefully appreciated
Thank you for your time
Hospital Palliative Care Team

I agree to completing the questionnaire and understand that it is voluntary

Signed _____

Date

TETLA YA GO DIRA DIPATLISISO**Tlokomela gore dipotso tseo re go botsang tsona ga o patelelwe go di araba**

[i.e.ga o sa batle go araba o ka dira jalo]

Dipotso di tla tshwanela go arabiwa pel ga HPCT e fitlha,le fa morago ga e setse e fitlhile [i.e o tla botswa dipotso ga bedi]

Tirisano mmoga ya gago re tla e itumelela .Re lebogela nako le matsapa a gago

Ke dumela go araba dipotso,ebile ke tlhalogangwa gore ga ke pateledi-we

Tsaeno _____

Letsatsi

IMVUME EMVA KOKUCHAZELWA

Yazi ukuthi imibuzo awuphoqelewe ngayo.

Unelungelo lokwenqaba,uma umgavumelani nayo.

Imibuzo sizocela uyiphendule iHPCT ngemuva nangaphambi kokuba seyizile , kuzoba kabili izikhathi.

Usizo lwokho luzoba uncedo kithini.

Siyabonga isikhathi sakho.

Ngiyavuma ukuphendula imibuzo ngiqonda futhi ukuthi angiphoqelekile.

Sayina _____

Usuku

7.2 Appendix B:**FACT G questionnaire in English**

Below is a list of statements that other people with your illness have said are important. **By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.**

<u>PHYSICAL WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
GP1	I have a lack of energy.....	0	1	2	3	4
GP2	I have nausea.....	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family.....	0	1	2	3	4
GP4	I have pain.....	0	1	2	3	4
GP5	I am bothered by side effects of treatment.....	0	1	2	3	4
GP6	I feel ill.....	0	1	2	3	4
GP7	I am forced to spend time in bed.....	0	1	2	3	4

<u>SOCIAL/FAMILY WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
GS1	I feel close to my friends.....	0	1	2	3	4
GS2	I get emotional support from my family.....	0	1	2	3	4
GS3	I get support from my friends.....	0	1	2	3	4
GS4	My family has accepted my illness.....	0	1	2	3	4
GS5	I am satisfied with family communication about my illness.....	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support).....	0	1	2	3	4

Q1

Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box and go to the next section.

GS7

I am satisfied with my sex life..... 0 1 2 3 4

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

EMOTIONAL WELL-BEING

		Not at all	A little bit	Some- what	Quite a bit	Very much
GE1	I feel sad.....	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness....	0	1	2	3	4
GE3	I am losing hope in the fight against my illness.....	0	1	2	3	4
GE4	I feel nervous.....	0	1	2	3	4
GE5	I worry about dying.....	0	1	2	3	4
GE6	I worry that my condition will get worse.....	0	1	2	3	4

FUNCTIONAL WELL-BEING

		Not at all	A little bit	Some- what	Quite a bit	Very much
GF1	I am able to work (include work at home).....	0	1	2	3	4
GF2	My work (include work at home) is fulfilling.....	0	1	2	3	4
GF3	I am able to enjoy life.....	0	1	2	3	4
GF4	I have accepted my illness.....	0	1	2	3	4
GF5	I am sleeping well.....	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun.....	0	1	2	3	4
GF7	I am content with the quality of my life right now.....	0	1	2	3	4

FACT G which was compiled by Dr David Cella, Ph.D.
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7.3 Appendix C: FACT G scoring guidelines

FACT-G Scoring Guidelines (Version 4)

- Instructions:*
1. Record answers in "item response" column. If missing, mark with an X
 2. Perform reversals as indicated, and sum individual items to obtain a score.
 3. Multiply the sum of the item scores by the number of items in the subscale, then divide by the number of items answered. This produces the subscale score.
 4. Add subscale scores to derive total FACT-G score. *The higher the score, the better the QOL.*

<u>Subscale</u>	<u>Item Code</u>	<u>Reverse item?</u>	<u>Item response</u>	<u>Item Score</u>
PHYSICAL WELL-BEING (PWB) <i>Score range: 0-28</i>	GP1	4 -	_____	= _____
	GP2	4 -	_____	= _____
	GP3	4 -	_____	= _____
	GP4	4 -	_____	= _____
	GP5	4 -	_____	= _____
	GP6	4 -	_____	= _____
	GP7	4 -	_____	= _____

Sum individual item scores: _____

Multiply by 7: _____

Divide by number of items answered: _____ = **PWB**

subscale score

SOCIAL/FAMILY WELL-BEING (SWB) <i>Score range: 0-28</i>	GS1	0 +	_____	= _____
	GS2	0 +	_____	= _____
	GS3	0 +	_____	= _____
	GS4	0 +	_____	= _____
	GS5	0 +	_____	= _____
	GS6	0 +	_____	= _____
	GS7	0 +	_____	= _____

Sum individual item scores: _____

Multiply by 7: _____

Divide by number of items answered: _____ = **SWB**

subscale score

EMOTIONAL WELL-BEING (EWB) <i>Score range: 0-24</i>	GE1	4 -	_____	= _____
	GE2	0 +	_____	= _____
	GE3	4 -	_____	= _____
	GE4	4 -	_____	= _____
	GE5	4 -	_____	= _____
	GE6	4 -	_____	= _____

Sum individual item scores: _____

Multiply by 6: _____

Divide by number of items answered: _____ = **EWB**

subscale score

**FUNCTIONAL
WELL-BEING
(FWB)**

Score range: 0-28

GF1	0	+	_____	= _____
GF2	0	+	_____	= _____
GF3	0	+	_____	= _____
GF4	0	+	_____	= _____
GF5	0	+	_____	= _____
GF6	0	+	_____	= _____
GF7	0	+	_____	= _____

Sum individual item scores: _____

Multiply by 7: _____

Divide by number of items answered: _____ = **FWB**

subscale score

TOTAL SCORE:

Score range: 0-108

_____ + _____ + _____ + _____ = _____ = **FACT-G**
Total score
 (PWB score) (SWB score) (EWB score) (FWB score)

*For additional guidelines please refer to the Administration and Scoring Guidelines in the manual or at www.facit.org.