

**AN EVALUATION OF THE EFFECTIVENESS OF THE HIV/AIDS PALLIATIVE
CARE PROGRAMME AT CHRIS HANI BARAGWANATH HOSPITAL**

BY

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RESEARCH DISSERTATION

Submitted in fulfilment of the requirements for the degree of
MASTER OF PUBLIC HEALTH

in the

SCHOOL OF PUBLIC HEALTH

at the

UNIVERSITY OF LIMPOPO

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2009

DECLARATION

I, Morero Elizabeth Leseka, declare that the thesis hereby submitted to the University of Limpopo for the degree of Master of Science in Public Health and filed for research has not been previously submitted by me for a degree at this or any other University; that it is my own work in design and execution, and that all materials contained herein has been duly acknowledged.

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DEDICATION

I dedicate this study to the improvement of the quality of life during the care of millions of South Africans infected and affected by the scourge of HIV/AIDS, and to my husband Johannes Leseka, who has always supported me in my endeavours to contribute to the improvement of the care and support of people living with HIV/AIDS.

ACKNOWLEDGEMENTS

I wish to thank many people who gave me the encouragement, the experience and support when gathering information to consolidate a report for this research, most of all the participants who gave me the generosity of their time to gather the information in this report. My immeasurable gratitude goes to my supervisor, Professor Supa Pengpid without whose guidance and persuasion this project would have been impossible to complete, the academic and administrative personnel at the School of Public Health, for their support during my studies. My sincere gratitude to Dr Allison Russell and her palliative care team and Dr Manning and the Chris Hani Baragwanath management, it was their dedication that prompted me to engage myself in this kind of research project.

ABSTRACT

Background: An understanding of the effectiveness of the hospital-based palliative care programme and the extent to which it changes the way patients are managed in the general medical wards is required, in order to develop evidence-based palliative care guidelines for Public Hospitals on the management of HIV/AIDS patients.

Purpose: The study aimed to identify and describe the effectiveness of the Palliative Care programme on the management of HIV/AIDS patients at Chris Hani Baragwanath Hospital. The objectives of the study included to:

- Determine the proportion of HIV positive patients admitted into Chris Hani Baragwanath general medical wards accessing services of a hospital-based palliative care team
- Identify the care and support needs experienced by HIV positive patients
- Compare the frequency of the met and unmet needs of HIV positive patients in those referred as opposed to those not referred to the hospital-based palliative care team

Methods: Non-random quota sampling of 50 HIV positive patients confirmed by an ELISA test, and admitted with HIV related illnesses were selected from admission records of medical wards in Chris Hani Baragwanath Hospital. 8 (16%) of the patients were too ill to communicate, 12 (24%) declined the interview and 30 (60%) gave consent to be interviewed. The data was collected using researcher administered questionnaires, and captured on Microsoft Excel 2003. Descriptive statistics were analyzed using STATA 10. Participants were assessed for enrolment into the hospital-based palliative care programme, common palliative care needs experienced and the frequency of identification and provision of palliative care needs provided for patients in the medical wards with focus on physical symptoms, pain, psychosocial problems, integration of care and counselling needs. The group was further divided into those under a palliative care program and those not under palliative care, for further data analysis.

Results: Findings revealed that very few patients (27%) with HIV&AIDS were accessing services of the hospital-based palliative care. Significant proportion (67%-77%) of HIV infected patients were experiencing physical symptoms, pain and psychosocial problems requiring palliative care interventions. Further findings revealed that for those participants who were not referred for the palliative care programme, symptoms and pain complaints were not effectively identified and treated by health personnel. Provision of psychosocial and spiritual support was inadequate and that the quality of life for HIV/AIDS patients was compromised due to lack of comprehensive and integrated holistic care. These components were found to be effectively addressed amongst the referred group.

Conclusion and recommendations: Hospital-based palliative-care has limited effectiveness due to the small size of the team which is working against demands from increasing numbers of HIV positive patients. All health providers working in medical wards need to be trained in palliative care, to develop a capacity to integrate palliative care principles into the routine medical care of HIV/AIDS patients.

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LIST OF ABBREVIATIONS AND ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ANC	Ante-natal care
CCMT	Comprehensive HIV/AIDS Care, Management and Treatment plan
DOH	Department of Health
ELISA	Enzyme-linked immunosorbent assay
GDOH	Gauteng Department of Health
HDA	Health & Development Africa
HIV	Human Immune-deficiency Virus
ICHBC	Integrated Community Home-based Care
MRC	Medical Research Council
NGO	Non-governmental Organization
NSAIDS	Non-steroidal anti-inflammatory drugs
NSP	HIV&AIDS and STI Strategic Plan for South Africa 2007-2011
OI's	Opportunistic Infections
PEPFAR	The President's Emergency Plan for AIDS Relief (U.S)
PLHIV	People Living With HIV/AIDS
STI	Sexually Transmitted Infections
WHO	World Health Organization

LIST OF OPERATIONAL DEFINITIONS

Adjuvant-analgesics - are drugs which are not analgesics, and are primarily used for other indications, but can produce analgesia in certain situations such as in nerve pain.

Break-through pain- is an episodic unpredictable pain which occurs between regular dosage intervals.

Comprehensive care –a system of holistic or total patient care that considers physical, emotional, social, economic and spiritual needs of a person.

Continuum of care – is a system of health care delivery, which guides and tracks a patient over time through comprehensive array of health services, spanning all levels of intensity of care.

Distributive justice – refers to fairness in allocation of resources to various members of community. It considers total amount of *what* is being distributed, distribution *procedure* and pattern of distribution *results*.

Integrated care – describe a system of health care provision, where teams of health care providers work together to provide patient care. Also defined as a type of team-oriented health care system which may be implemented through consultative, collaborative, parallel referral or integrative manner.

Interdisciplinary approach- an approach to health care provision where different medical disciplines work together in an equal collegial relationship to provide integrated patient care.

Pharmacokinetics – absorption and distribution of the drug in the body

Referred or not referred to palliative care – enrolled or not enrolled into the hospital-based palliative care programme

Respite care – a short-term temporary relief for those taking care of a sick family member, usually provided through in-patient or day-care facilities.

CHAPTER 1

INTRODUCTION AND BACKGROUND

1.1 Introduction:

HIV&AIDS is one of the major challenges facing South Africa today. Of the 48 million South Africans estimated in the last census, 5,7 million are estimated to be infected with HIV (UNAIDS, 2008).Of the nine provinces of South Africa, Gauteng ranks the second highest in HIV prevalence, whose adult HIV prevalence (extrapolated from the annual Antenatal Prevalence Survey), is estimated at 29,3%. One of its four districts, Johannesburg Metropolitan district is leading at 31% prevalence (DOH, 2008).

The Chris Hani Baragwanath hospital statistics indicate that an average of 45% of medical patients were admitted with HIV related symptoms during the winter of 2002 and that 43% of deaths resulted from AIDS (www.chrishanibaragwanath.gov.za).

With the growing numbers of People Living with HIV (PLHIV) requiring medical care, the demand for resources is increasing and challenging for the South African national health system. Effective models of care should be identified to ensure accessible, acceptable and affordable comprehensive care for HIV infected and affected people.

This Chapter intends to provide an orientation of the background to the study and problem statement.

1.2. Background

The Cabinet of South Africa approved Operational Plan for Comprehensive HIV / AIDS care, management and treatment for South Africa (CCMT). Palliative Care is included as one of the elements of comprehensive care for HIV/AIDS in this plan (DOH, 2003).

Palliative care is a new concept in South Africa; its role is to have patients assessed by the palliative care team, similar to other consultative services, using current best practices in palliative and HIV care. Consultations address issues such as pain and symptom management, advance care planning, goals of care, psychosocial concerns for patients and families, pastoral care, and legal-ethical concerns. In addition to working closely with primary HIV care providers, the consultation team also facilitates appropriate linkages to hospice, home care, and other end-of-life services as necessary. Bereavement support is provided for families and caregivers (O'Brien & Dunn, 1998).

Chris Hani Baragwanath is the first hospital in Gauteng to engage the services of a well established interdisciplinary hospital palliative care team since September 1999, under the directorship of Dr Russel, followed by Pretoria Academic and Johannesburg hospitals. This is a small team comprising of three registered nurses who have to provide palliative care for patients referred to them from the medical, gynaecology and at times the surgical wards, catering for both cancer and HIV/AIDS sufferers with Dr A. Russel as consultant, palliative care coordinator and project manager.

In September 2002 the project completed three years and the hospital took over the running of the project as one of the hospital services. In 2003 the N'doro Model of palliative care was established by the Perinatal HIV Research Unit, a subsidiary of the University of the Witwatersrand, with support from the Development Cooperation of Ireland (DCI) and is currently providing support to the initial hospital-based palliative care team.

1.3. Problem statement

There is an overwhelming increase in the number of admissions of HIV positive patients requiring palliative care. This places great demands for financial, material and human resources on hospital-based palliative care programmes. It is therefore important to establish how the care and support needs of PLHIV are being met in the general medical wards as part of the comprehensive HIV care advocated for in the Operational Plan.

1.4. Research questions

The research questions for the study are:

- What proportion of HIV positive patients admitted in Chris Hani Baragwanath hospital's general medical wards are accessing the services of the hospital-based palliative care programme?
- What are the care and support needs of HIV positive patients admitted to the hospital?
- Can the palliative care needs of PLHIV be effectively met through general medical care when a hospital-based palliative care team is not available?

1.5. Aim

The aim of the study was to identify and describe the effectiveness of the Palliative Care programme on HIV/AIDS patients at Chris Hani Baragwanath Hospital.

1.6. Objectives

The objectives of the study are:

- Determine the proportion of HIV positive patients admitted into Chris Hani Baragwanath general medical wards who are accessing services of a hospital-based palliative care team.
- Identify the care and support needs experienced by HIV positive patients.
- Compare the frequency of the met and unmet needs of HIV positive patients in those referred compared to those not referred to the hospital-based palliative care team.

1.7. Rational of the study, justification or significance of the study

The South African Operational plan for comprehensive HIV/AIDS care, embraces the element of palliative care .The HIV/AIDS and STI Strategic Plan for South Africa 2007-2011 (NSP) has as one of its main goals, made efforts to increase access to treatment, care and support to 80% of people infected and affected by HIV/AIDS. Improvement of the quality of care offered to PLHIV, and strengthening the health system to remove barriers to access are inherent objectives of attaining this NSP goal. (DOH,2007). For effective planning and implementation of palliative care for PLHIV, evidence-based guidelines and policies are essential for care givers and program managers. Very few studies have been undertaken on palliative care provision in Africa

and in South Africa in particular. Findings from this study will assist policy makers and health authorities to design appropriate palliative care services for increased numbers of PLHIV against the backdrop of limited resources.

1.8. Conclusion

This study assessed the effectiveness of care provided to HIV/AIDS patients in general medical wards without intervention from the palliative care team and compares this care against that received by the few HIV/AIDS patients under the care of the hospital-based palliative care team.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

This chapter reviews current literature in proportion to PLHIV accessing services of hospital-based palliative care programmes, the care and support needs experienced by PLHIV admitted to hospitals and a comparison of the extent of met and unmet needs for people both receiving and not receiving palliative care.

2.2 Proportion of PLHIV accessing the services of a hospital-based palliative care programme

2.2.1 When should PLHIV access a palliative care programme?

1. Lack of consensus on the operational definition of palliative care has much bearing on the extent to which patients access palliative care services. The perception of what palliative care is, influences intervention strategies with regards to when it should be commenced and where it should be offered. Palliative care was developed in the United Kingdom and later in Canada in response to the health needs of terminal cancer patients during the terminal stage of the disease (Foley, Aulins & Stjemsward, 2003). Equating palliative care to terminal care implies that PLHIV will not be offered palliative care until they display symptoms of terminal HIV disease.

The NSP and Gauteng Clinical guidelines for HIV/AIDS management, in prioritising palliative care also implies the view of terminal care, and relates it mainly to home – based care (HBC). Terminal implies that all is finished and that nothing else can be done for the individual. HIV/AIDS defied all these definitions - demanding supportive approach within a broader comprehensive care from the time of diagnosis, and beyond death and bereavement, and during early stages of the disease until the advanced stage. Relating palliative care to home-based care means that it should be provided by “...*formal or informal care givers in order to promote, restore and maintain a person’s maximum level off comfort, function health, including care towards a dignified death*” (WHO, 2002) on HBC definition.

Palliative care is defined as “... *active total care of patients whose disease is not responsive to curative treatment.*” or as “*management of patients with active, progressive, far advanced disease for whom prognosis is limited and the focus of care is the quality of life*” (O’Neil & Fallon, 1997) This definition implies that palliative care is synonymous with terminal care and focuses on the quality of life rather than longevity. The definition further implies that no palliative care could be offered during the initial phases of the disease or when curative intentions are still effective, and that the palliative care principles, namely patient and family involvement, interdisciplinary approach and holistic patient care, will be applicable during the terminal phase only.

Sanei (1998) describes how HIV/AIDS has challenged the above traditional views of palliative care. She indicates the difference between cancer and HIV/AIDS in which the former has the relatively clear demarcation between curative care and palliation,

whereas in the latter this demarcation is not clear. The paradigm shift is recommended for the ethical and philosophical basis of palliative care, so that the definition should be expanded to reflect a more holistic approach in treating people living with HIV/AIDS.

The concept of palliative care grew out of pain relief and comfort measures for cancer patients. Since AIDS is a fatal disease with many curable manifestations, the distinction between active, curative treatment and palliation is blurred. As a result, current definitions of palliative care define this medical care service as a more holistic one that begins earlier in the course of a chronic, fatal medical condition (UNAIDS, 2000; Sims & Moss, 1995).

WHO's definition supports this paradigm by adding this phrase to the original definition: "... *many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anti-cancer treatment*" (WHO, 2002).

It is against this background that awareness has been created among health professionals on the new concept of palliative care to ensure that it is integrated into continuum of care for PLHIV rather than withholding the services for the terminal stage.

2.2.2. Who should offer palliative care to PLHIV in the medical wards?

In the N'doro Project's annual report of 2004 it is reported that hospital palliative care teams comprises of two full time and one part-time nurses, supervised by a consultant physician. They run a hospital palliative consulting service, and thus work in all wards providing recommendations for pain and symptom relief. This situation indicates one of

the serious constraints affecting a proportion of PLHIV who access the services of a hospital-based palliative care programme. Palliative care should not be treated as a stand-alone programme, but core-palliative care competencies should be incorporated into HCW's daily routine, using a specialist consulting service when required. This approach will ensure that a better proportion of PLHIV needing palliative care access it promptly provided by staff on site.

In 2001 the Ethics Institute of South Africa conducted an ethical audit research at Chris Hani Baragwanath Hospital. The findings from this audit highlighted staff- shortages and increased workload as key human resource issues, and also a source of stress for various categories of staff (Landman, Mouton & Nevhutali, 2001). These are the issues that need to be addressed to ensure that patients readily access required services like palliative care, using models that are context specific to increase programme coverage.

Alan Barnad, in the article he wrote on the Palliative Care Society of South Africa, argues that the benefit of improved quality of life among patients referred to the hospital palliative care team is invaluable and should be available to every patient. Palliative care therefore extends into the mainstream medical care, and that the principles of palliative care should be incorporated into everyday medical practice (www.palliativecaresociety.co.za).

2.2.3. How should palliative care access be improved?

The Korean Declaration of March 2005 states that palliative care is an interdisciplinary approach incorporating nursing, medicine, social work, pastoral care, physiotherapy and

occupational therapy, but stated access to trained palliative care professionals as a worldwide problem (www.palliativecaresociety.co.za). This implies that with adequately trained nurses and doctors, including other professionals, palliative care could be offered as part of the routine multidisciplinary team within the hospital. This will address the issues of staff shortages limiting referral of patients to the hospital-based palliative care team

The interdisciplinary team concept is also highlighted in the Operational Plan for HIV&AIDS care, management and treatment of South Africa 2003, and has been the key criteria for accreditation of sites for provision of antiretroviral therapy (ART) (DOH, 2003).

It is against the above discussion that the study sought to investigate the proportion of PLHIV admitted to the Chris Hani Baragwanath hospital, that are receiving the services of a palliative care programme at a particular point-in time, in order to make conclusions about effective palliative care coverage through the present model of palliative care .

2.3. Care and Support Needs of PLHIV

The care and support needs of PLHIV are classified as physical, psychosocial and spiritual. In this section an attempt is made to identify those problems which will generate these needs in the patients. It is important to highlight those symptoms likely to affect the patient in palliative care settings for appropriate evaluation of implementation effectiveness.

2.3.1. Common symptoms in palliative care

These are common symptoms likely to affect the AIDs patients (O'Brien, et al., 1998; Foley, et al., 2003).

Physical	<p>Pain- associated with GIT, respiratory and neurological conditions or OI's. The pain may be somatic, visceral, bone or neuropathic (nerve) pain</p> <p>Cough- manifesting in tuberculosis, pneumonia, bronchitis, pneumocystis carinii pneumonia and Karposis Sarcoma</p> <p>Diarrhoea associated with a variety of causative organisms</p> <p>Anorexia, nausea and vomiting</p> <p>General malaise, weakness and fatigue</p>
Psychosocial	<p>Rejection by family and partner</p> <p>Stigmatization by the community</p> <p>Unemployment, poverty and homelessness</p> <p>Multiple losses e.g. job, relationships, future, body image or body function, etc</p>
Spiritual and emotional	<p>Meaning for life ,Guilt</p> <p>Fear of death</p> <p>Depression</p> <p>Dementia /confusion</p>

It has been indicated in the preceding sections that palliative care developed from the need to provide compassionate care for terminal cancer patients. Most of the physical problems experienced by AIDS patients may be compounded by the differences and

intensity of the psychosocial problems and challenges facing them which may not compare with those of cancer patients. Comprehensive assessment and identification of these problems is essential for effective patient care planning. These differences were reported by Russell and Schneider and identified below:

1. Predominantly younger age group affected (0 – 5 years of age; 16 – 49 years of age)
2. Multisystem disease with multiple problems
3. Co-existing diagnoses
4. Sudden, dramatic changes in condition – difficulty in diagnosing terminal phase
5. Need for active treatment with palliation e.g. treatment of opportunistic infections
6. Lengthy dying process e.g. a patient may be unconscious for weeks or more
7. Changing pattern of disease and treatment including poly-pharmacy
8. Isolation, stigma with possible lack of compassion for patient and family
9. Possible lack of family and support structures
10. Problems associated with poverty

(Sims& Moss, 1995; Russell & Schneider, 2000).

Richard Harding in his article in the *Lancet*, in 2005, also looks at the difference between palliative care needs in Africa and those of the developed countries. He highlights palliative care needs in African countries as those including home and respite care, pain and symptom control, financial, emotional and spiritual support, and also food, shelter, legal assistance and school fees. The author further indicates the influence of psychosocial issues in physical symptoms e.g. a disease-related pain is difficult to manage in patients with hunger pains. Research into the pathophysiology of pain and diseases has demonstrated the effect of emotion on the perception of pain (Browde,

2001). Another AIDS related feature of the difference between African and developed countries is the size of the orphan population, which is huge in Africa (Harding & Higgison, 2005). This highlights the need for early identification of potential orphans through comprehensive palliative care programmes, in order to assist the patient and family in planning for the future.

The differences as specified above may tend to generate specific palliative care needs in HIV/AIDS patients which may differ from those of cancer e.g. because of age it might be easier to assist the cancer patient and family to accept the imminent death than it could be for a young AIDS patient and family. Elderly cancer patients may enjoy support and care from his/her own mature children, whilst the AIDS victims are likely to be young, with little children depending on support from relatives or their own parents who might be too old to care for them at times. HIV/AIDS patients frequently worry about the future of their children; they want reassurance that their children will be fed, housed and schooled after they are gone (Sanei, 1998). These factors will have to be considered in this study when analysing the care and support needs of the HIV/AIDS patients, including any impact they may have on effectiveness and efficiency of the palliative care programme.

Studies in many countries highlight pain relief, symptom management, psychosocial and spiritual support, nutrition and financial support as the predominant palliative care needs for PLHIV. These studies further suggests that the needs likely not to be met are those for pain relief and symptom management, psychological support, training of family care-givers, financial support and food provision (Uwimana & Struthers, 2007).

Palliative care needs of the PLHIV are required to be promptly and accurately identified in order to ensure appropriate and timely intervention to relieve them. PLHIV's needs for pain relief and symptom management are commonly under-diagnosed and these may contribute to poor adherence and engagement with other HIV specific therapies (Selwyn, 2008).

2.4. Comparison of the frequency of met and unmet needs for PLHIV under palliative care programme to those of PLHIV not under palliative care programme.

2.4.1. What constitutes effective palliative care?

The World Health Organization defines palliative care as an “approach that improves quality of life of patients and their families facing problems associated with life-threatening illness, through prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (WHO, 2002). The result of early intervention with active palliative care is a better quality of life for patients and their families.

Palliative care includes all aspects of care, medical and non-medical, and as such is described as total care (Gwyther & Cohen, 2008). The Operational Plan for Comprehensive HIV/AIDS care, management and treatment embraces palliative care as one of the elements of HIV/AIDS care. Comprehensive palliative care, on the other hand, is essential for the health and wellbeing of PLHIV.

The President's Emergency Plan for AIDS Relief (PEPFAR) developed guidance for HIV/AIDS Palliative Care. In this guidance PEPFAR takes the new broader view of palliative care which encompasses care provided from the time that HIV is diagnosed, and throughout the continuum of HIV infection (www.pepfar.gov). Categories of palliative care identified in the guidance document are comparable with those advocated for by UNAIDS, namely:

- Clinical Care- generally provided by Dr's and Nurses to address biomedical problems
- Psychological care –to address non-physical suffering of patients and families
- Spiritual care – addresses major life events that causes people to question themselves
- Social care-assisting individuals and families to maintain linkages to and use of care

2.4.2. Components of palliative care

A USAID discussion paper entitled "Palliative Care for HIV/AIDS in Less Developed Countries" describes the following medical elements of palliative care:

- Pain control - Treat mild pain with acetaminophen and/or non-steroidal anti-inflammatory drugs (NSAIDs), followed by the treating of moderate pain by adding codeine, and severe pain by adding morphine. Morphine is not available to most people in less developed countries, constituting a point of intervention.
- Nutritional support - Poor intake, increased metabolism, decreased absorption, and diarrhoea all contribute to nutritional deficiency among persons with

HIV/AIDS. 1) Assess nutritional condition early in the course of HIV, and particularly during times of Opportunistic Infections. 2) Provide a balanced diet of locally available foods complete in protein, calories and fibre. Pay attention also to hydration and foods rich in vitamins and minerals. WHO guidelines exist for appropriate nutrition and for special preparation of food (food safety).

- Integration of prevention into care, where counselling is the driving force for preventive intervention, e.g. lifestyle modification and sexual behavioural change, to prevent re-infection and spread of HIV to others
- Prevention/Treatment of Opportunistic Infections (OI's).
- Medical Treatment for Symptom Management - This includes symptomatic management of fever, nausea and vomiting, diarrhoea, skin and genital problems, cough and difficulty in breathing, tiredness and weakness, anxiety and depression, mental confusion and dementia.
- Alternative/Traditional Healing - WHO estimates that 80 percent of the worldwide population uses some types of alternative therapy. The use of alternative therapies may signal the active participation of patients in decision-making and assuming control of their health. Herbs, in particular, are commonly used. A few herbs have been documented to have detrimental effects, but most have no effect or lead to subjective improvement in symptoms and quality of life.
- Counselling/Psychosocial support- this should include counselling, psychosocial care, emotional and spiritual support, bereavement support for families and caregivers.

- Psychosocial care including social assistance and legal issues.

2.4.3. Strategies for meeting the palliative care needs of PLHIV

Uwimana&Struthers, in their article in the Journal of Social Aspects of HIV&AIDS, reported that their study found that despite the health care services being available for PLHIV and their families, many of their palliative care needs were still unmet. Obstacles for the provision of palliative care were identified as, inadequate staff and limited capacity for human resources in terms of policies, skills and training

2.4.3.1. Integration with disease modifying care:

Several studies on palliative care recommend integration of palliative within curative care. If the palliative care needs of the PLHIV are to be met, a palliative care programme should be available within the general patient care. Instituting palliative care does not imply withdrawal of curative treatment (Gwyther, 2008; Browde, 2001).

2.4.3.2. Interdisciplinary approach

Palliative care is based on interdisciplinary care that incorporates medicine, nursing, social work, pastoral care, physiotherapy, occupational therapy and other related care. This approach is advocated by PEPFAR and reaffirmed in most of the palliative care literature. It is violation of the PLHIV's rights to care, if access to available palliative care services is not facilitated (Gwyther, 2008; Harding, 2008; www.pepfar.com).

2.5. Conclusion

There is an agreement in the literature about the need for provision of palliative care for HIV/AIDS patients early in the course of disease. The care should include symptom management, pain control, psychosocial and spiritual care, involvement of an interdisciplinary health team, referral for continuum of care and dealing with death and bereavement

During the process of literature review it was noted that most of the overseas based literature discusses palliative care in relation to cancer terminal care, whilst the African-based (especially the Sub-Saharan) literature focuses on HIV/AIDS palliative care. It is however important to note that whatever the focus of the disease is, the principles of palliative care remains the same, and it is on this basis that the relationship between the hospital based palliative care and the HIV/AIDS palliative care was examined

CHAPTER 3

METHODOLOGY

3.1 Study Design

This research project is a descriptive cross sectional study carried out between March and June 2004, in the Chris Hani Baragwanath Hospital medical wards. This quantitative study used face-to-face interviews with HIV&AIDS patients receiving general medical care from the ward staff as well as patients receiving care from a specialist palliative care team in the hospital general medical wards.

3.2 Study setting and site selection

The Chris Hani Baragwanath Hospital is a large 3000 bed, urban academic hospital, situated about 15 kilometres from Johannesburg city. According to Guinness Book of Records 1994, it is the largest hospital in the world. It serves mostly Soweto residents and the surrounding informal settlements extending into Sedibeng and Westrand districts. The Department of Internal Medicine is the largest with 776 beds, about 45% of which are occupied by HIV positive patient ,majority of whom are admitted with opportunistic infections and symptoms characteristic of the advance clinical HIV disease (www.Chrishanibaragwanathhospital.co.za). The prevalence of poverty, unemployment and homelessness compound the management of AIDS patients at this hospital.

The site was selected because of its existing hospital-based palliative care programme catering for both HIV&AIDS and cancer patients and its HIV&AIDS disease burden.

The hospital's academic status allows for an interdisciplinary team concept to be best practiced through a discipline of ward rounds and informal discussions for the benefit of members of the team and the patients.

3.3 Study Population

The study population included 527 HIV positive male and female patients, 18 years and older, admitted in three general medical wards of the Chris Hani Baragwanath hospital, namely ward 35, ward 38 and ward 23, with HIV/AIDS related illnesses and registered in the ward admission records.

3.4 Study Sample

Based on the population of 527, thirty (30) patients diagnosed with HIV/AIDS related illnesses that were admitted to the medical wards of the Chris Hani Baragwanath Hospital_during March 2004 to June 2004 were selected using a purposive sampling method. According to Uwimana and Struthers (2007) purposive sampling is used in special situations in which the researcher selects unique cases that are especially informative for in-depth investigation. Since purposive sampling is not a mathematical method, no sampling calculation was used.

Inclusion criteria were 18 years and older patients, sero-positive with cognitive ability to comprehend and communicate in at least one of the 11 South African official languages. Exclusion criteria were PLHIV under 15 years, and those with cognitive problems and disabilities such as blindness or deafness.

3.5 Data Collection

Data was collected through a structured questionnaire administered by the researcher completed during face to face interviews conducted with participants during the period March to June 2004. The three months quoted was the period when the researcher was able to be released from her workplace for the purpose of data collection.

The questionnaire to assess the PLHIV access to palliative care, identification of their care and support needs and the care provided for the identified needs was self-developed by the author. A total of forty (40) items were included within seven sections covering the following aspects:

- patient category in relation to specialist palliative care referral status,
- demographic profile
- admission information
- problems experienced by patient,
- symptom management,
- pain management
- psychosocial care.

The questionnaire was pretested on five HIV positive patients to ensure reliability and validity after which some items were re-worded, included or added sub sections to ensure that the instrument measure was able to measure that which it was intended to measure and its wording is not ambiguous.

Due to the wide range of indigenous languages spoken by the majority of patients at Chris Hani, the questionnaire interpretation was done verbally during the interview according to the individual participant's language, because it was researcher administered. Most black patients at Chris Hani Baragwanath are likely to speak any one or more of the five indigenous languages (e.g. Sotho, Zulu, Xhosa, Tsonga, Venda etc.) including Afrikaans for most Colored people and English for all other races including foreigners.

3.6 Data Analysis

The quantitative data was captured in the Microsoft Excel worksheet with the aid of codes. The services of a statistician were utilized and the STATA 10 software program was used. Data was analysed for enrolment into the hospital-based palliative care programme, common palliative care needs experienced and the extent to which identification and provision of palliative care needs was provided for patients in the medical wards with a focus on physical symptoms, pain, psychosocial problems, integration of care and counselling needs. Descriptive statistics were used in this study, and frequency reported in terms of numbers and percentages. Tables and graphs will be used to present these statistics.

3.7 Ethical considerations

3.7.1 The ethical approval process

Ethical clearance was granted by the Research, Ethics and Publication Committee of the National School for Public Health, University of Limpopo (Project No.

NSPH/ST/2003/12) before the study commenced, in August 2003, where the researcher was a student. (See attached appendix 1).

3.7.2 Permission for the study

Permission to conduct this study was requested from Chris Hani Baragwanath Hospital CEO, Dr Brookman with an accompanying letter from my supervisor Ms Helen Lewis (See appendix 2). A written approval to conduct the study in the hospital was provided by Dr Manning on the 17th February 2004 (See attached appendix 2).

3.7.3. Ethical principles applied

Informed consent

The purpose of the study was explained to the individual patients and written consent was obtained prior to participation in the face-to-face interviews(See appendix3) Verbal translation by the researcher was done to ensure that the patient obtained a clear understanding of the contents in his/her own language.

Freedom of choice and non-coercion

Patients were further assured that they will still receive care from the hospital even if they choose not to participate in the study. No special incentives or payments were offered for participation.

Confidentiality

Participants were assured that information will be treated in confidence, and that no one could link them to completed questionnaires.

Non-maleficence

All patients were recruited individually before or after receiving routine medical care, and measures were taken to ensure that the study causes no physical or psychosocial harm to the patients.

3.8 Limitations of the study

A random sampling method was not possible due to the unique nature of the participants (PLHIV) who had to be selected discriminately from within the general population of medical patients. Scarcity of patients placed in palliative care programmes caused ineffective control samples for comparison on findings. The study was limited to a few medical wards in one hospital and cannot be generalised due to lack of randomization. Staff was not interviewed to examine negative findings against existing knowledge and skills in palliative care approach. Palliative care is a broad subject which resulted in too many variables being examined to make a coherent whole. Generally very ill patients in hospital therefore expressed their views within the context of people confronted with fear of possible death, possibility of anger or denial. Patients' conditions could also affect their ability to recall certain events.

CHAPTER 4

PRESENTATION AND DISCUSSION OF DATA

4.1 Introduction

This chapter discusses data analysis and interpretation against the study objectives, namely to:

- Determine the proportion of HIV positive patients admitted into Chris Hani Baragwanath general medical wards accessing services of a hospital-based palliative care team
- Identifying the care and support needs experienced by HIV positive patients
- Compare the frequency of the met and unmet needs of HIV positive patients in those referred compared to those not referred to the hospital-based palliative care team

A total of thirty (30) serologically confirmed HIV positive patients were admitted to the medical wards of the Chris Hani Baragwanath Hospital during March to June 2004 and were able and willing to participate in the study. They provided signed consent and were interviewed. The choice of medical wards was purposely selected since about 45% of patients in the medical wards were found to be admitted with HIV/AIDS related illnesses, and both male and female medical wards were included in the study.

4.2 .Response rate

The response rate was 100% since the questionnaire was researcher administered.

4.3. Data presentation and interpretation

The data is presented in line with the different sections of the study questionnaire namely:

- patient category in relation to the status of enrolment into hospital-based palliative care programme
- demographic profile
- admission information
- physical and psychosocial problems experienced by PLHIV
- symptom management
- pain management
- psychosocial care.

4.3.1. Descriptive Statistics

Five questions covered the socio-demographic characteristics of the respondents. One question identified the categorization of participants into those who were referred and those not referred to palliative care, two questions enquired about physical and psychosocial problems experienced by PLHIV, whilst twelve questions enquired about the participants' experience and perception of the management of their physical and psychosocial problems, including pain management by health professionals.

4.3.2. Frequencies.

Frequencies are the number of observations with or without attribute of interest and are displayed in terms of tables, and bar-charts (Dawson & Trapp, 2004) in this report. The

responses in this cite response alternatives include mainly “frequently”, “sometimes” or “not at all”, “adequate”, “inadequate” or “little”, “or none at all”, or “caring”, ”non-caring” or “indifferent”

4.4. Overview of socio-demographic characteristics of respondents

The socio-demographic characteristics of PLHIV who participated in the study are presented in Table 1 and Figure 1 below.

Table 1. Demographic profile (n=30)

	n	%
Gender		
Male	9	30
Female	21	70
Marital Status		
Married, cohabiting	1	3
Married, not cohabiting	3	10
Regular partner, cohabiting	9	30
Regular partner, not cohabiting	1	3
Single	11	37
Widowed	4	14
Divorced	1	3
Income		
Yes	27	90
No	2	7
Country of origin		
RSA	27	90
Botswana	1	3
Malawi	2	7

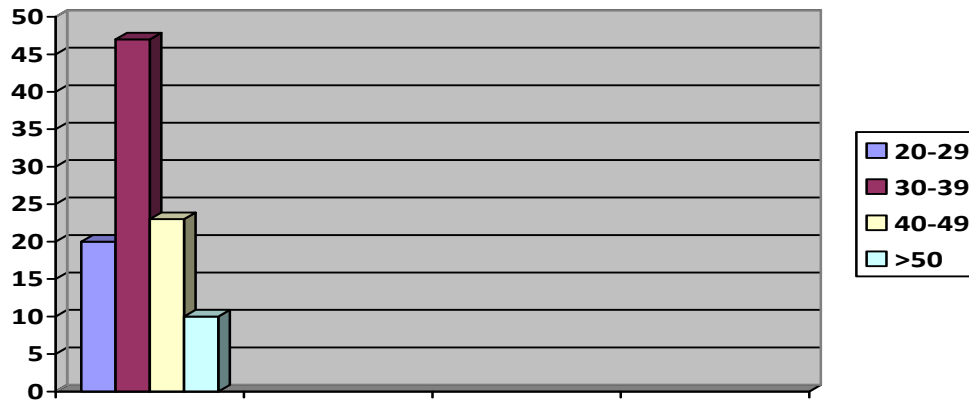


Figure 1: Age distribution of participants (n=30)

47% of participants were within the age group 30-39, consistent with the national distribution of HIV prevalence rate for this period (DOH, 2003). 90% of the participants indicated they have a source of income, but when asked to specify the source of income 30% (8) were dependent on government grants, whilst 60% were dependent on family members, only 4 had regular incomes. A significant proportion of the participants (67%) were single, or co-habiting with regular partners and 4 (13%) of the participants were married. 30% of the participants were males and 70% were females. Very few PLHIV were from countries outside South Africa (2 from Malawi, and 1 from Botswana)

4.5. Proportion of PLHIV under the Hospital Palliative care programme

Of the 30 participants, 8 (27%) were receiving specialist palliative care in addition to the general medical care.

4.6. Identified care and support needs of PLHIV

4.6.1. Physical symptoms experienced by PLHIV

Individual patients in both the referred and non-referred groups experienced more than one symptom. Frequency of physical symptoms experienced by all PLHIV who participated in the study is depicted in Figure 2 below:

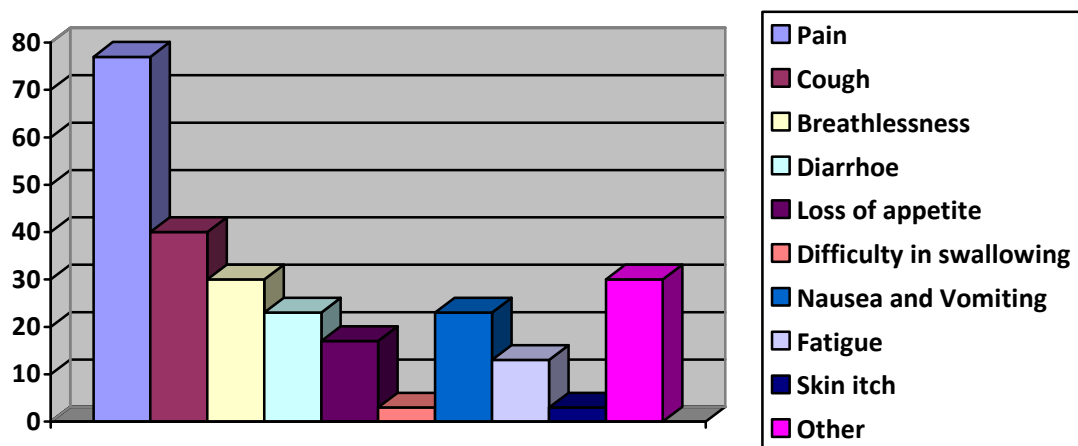


Figure 2: Frequency of physical symptoms reported by participants (n=30)

Pain (77%) was the most frequently reported symptom by participants, followed by cough (40%) and breathlessness (30%).

4.6.2. Psychosocial problems experienced by PLHIV

Table 2 displays the number of psychosocial problems experienced by individual participants in both categories of patients.

Table 2: Number of psychosocial problems experienced by each participant (n=30)

No. of problems	Referred		Not Referred		Total	
	n	%	n	%	n	%
0	1	12	6	27	7	23
1	2	25	8	36	10	33
2	3	38	6	27	9	30
3	2	25	1	5	3	10
4	0	0	1	5	1	4

Fisher Exact test: p=0.466

Individual patients in both referred and non-referred groups experienced more than one psychosocial problem. There was no significant relationship between problems experienced by PLHIV and Palliative care referral pattern. Common psychosocial problems experienced by PLHIV are displayed in Figure 3 below:

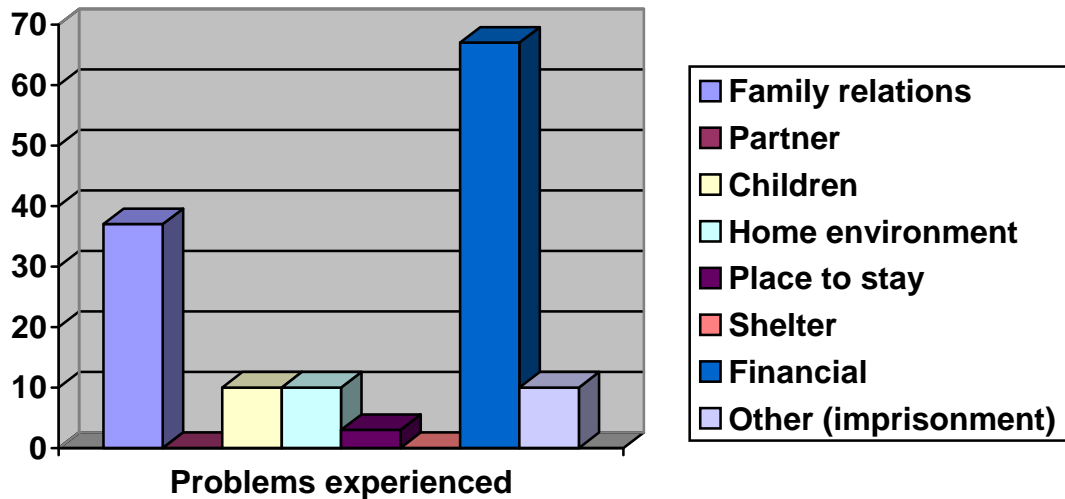


Figure 3: Frequency of Psychosocial problems reported by participants (n=23)

Financial problems (reported by 67% of participants) were found to be the most commonly reported problem, followed by family relationships (reported by 37% of respondents). These findings on financial problems were consistent with those from the demographic data where only 4 PLHIV had a regular income. Child problems seemed to be reported in direct proportion to the home environment.

4.7. Comparison of frequency of met and unmet needs for PLHIV under palliative care programme to those of PLHIV not under palliative care programme

4.7.1. Symptom Management

Table 3 below, displays frequency of the rating of health workers' response when PLHIV report that they are experiencing physical symptoms.

Table 3: Health workers attitude towards patients with physical symptoms (n=30)

	Referred		Not Referred		Total	
	n	%	n	%	n	%
Treatment received from nurses for your symptoms						
None	0	0	2	9	2	7 ψ
Little	3	38	10	48	13	45
Adequate	5	62	9	12	14	48
Treatment received from doctor for your symptoms						
None	0	0	0	0	0	0 \pm
Little	2	29	10	50	12	44

Adequate	5	71	10	50	15	50
Nurses attitude when you complain about symptoms						
Caring	6	75	11	50	17	56 π
Not caring	2	25	6	27	8	27
Indifferent	0	0	5	23	5	17
Doctors attitude when you complain about symptoms						
Caring	7	88	16	76	23	80 \ddagger
Not caring	1	12	2	10	3	10
Indifferent	0	0	3	14	3	10

ψ $p=0.833$; \pm $p=0.408$; π $p=0.331$ \ddagger $p=0.788$

There were no significant differences on reported doctors' attitude in referred (88%) and non-referred patients (76%). Respondents under a palliative care programme reportedly received adequate treatment for their symptoms from both nurses and doctors (69% and 71% respectively) whilst 50% of those not under the programme reported little treatment for their symptoms from both categories of health professionals.

About 80% of the patients in both categories reported doctors' attitude as caring when they complain about symptoms. Patients under palliative care reported that the attitude of both doctors and nurses as caring (88% and 75% respectively) whilst those not under palliative care perceived doctors attitude as significantly more caring (76%) than that of nurses (50%). There is a marked difference on nurse's attitudes reported as caring by referred patients (75%) and by non-referred patients (50%).

4.7.2. Pain management

Table 4: Frequency of Pain Management for PLHIV referred and those not referred to the palliative care programme (n=23)

	Referred		Not Referred		Total	
	n	%	n	%	n	%
Pain enquiry						
Frequent	4	100	9	50	13	59 ψ
Sometimes	0	0	3	17	3	14
Not at all	0	0	6	33	6	27
Person ask you about your pain						
Nurse	0	0	0	0	0	0 \pm
Doctor	3	75	9	82	12	80
Doctor/Nurse	1	25	2	18	3	20
Rate treatment reserved for pain management						
None	0	0	1	6	1	4 π
Inadequate	1	20	10	56	11	48
Adequate	4	80	7	38	11	48
Frequency at which pain medication given to patient						
Before experiencing pain	4	80	6	35	10	45 \dagger
When complain about pain	0	0	5	30	5	23
Already experiencing pain	1	20	6	35	7	32
Pain medication adjusted between treatment						
Yes	3	60	5	36	8	42 \dagger
No	2	40	9	64	11	58

ψ $p=0.296$; \pm $p=0.637$; π $p=0.461$; \ddagger $p=0.535$; \dagger $p=0.603$

Table 4 above depicts the experiences of PLHIV under a palliative programme and those not referred to the programme, on management of their pain symptom by health professionals.

There was significant differences found between patients referred and those not referred with regard to pain enquiry (100% and 50% reported frequent enquiry respectively), frequency at which pain medication is given to patients (80% and 35% reported medication being given before experiencing pain respectively) and adjustment of medication between treatments (60% and 36% reported yes to adjustment respectively). Overall, 59% of the patients reported that health care workers were frequently asking them about their pain. Eighty percent (80%) reported that doctors were always asking them about their pain

4.7.3. Psychosocial Care

Of the 23 (77%) respondents who reported to have psychosocial problems, 20% reported their problems, and 67% of these reported their problems to a palliative care nurse whilst 17% reported to ward sister. Majority of patients 76% chose not to report their problems. This may imply that the palliative care nurse is more approachable and has time for patients unlike the general medical ward sister.

Table 5 below, depicts the extent of counselling and HIV&AIDS disease related information provided to PLHIV by health care workers.

Table 5: Patient Counselling and Information on HIV/AIDS disease (n=30)

	Referred		Not Referred		Total	
	n	%	n	%	n	%
Disease aspect						
Nature of the disease	6	75	10	45	16	53
Disease treatment	7	88	1	5	8	27
Disclosure	6	75	1	5	7	23
Continuation of treatment after discharge	5	63	2	9	7	23
Care at home	6	75	1	5	7	23
Family support	5	63	0	0	5	16
Disease outcomes						
No cure	6	75	11	50	17	57
Shortening life	6	75	7	32	13	43
Death and dying						
Feelings about death and dying	7	88	1	5	7	23
Future planning	5	63	4	18	9	30
Staff discussing the disease with patient						
Nurse	2	25	3	14	5	16
Doctor	5	63	10	45	15	50
Counsellor	0	0	0	0	0	0
Other	1	12	1	5	2	7

ψ $p=0.833$; \pm $p=0.408$; π $p=0.331$; \ddagger $p=0.788$

On average 75% of patients referred to palliative care programme received counselling on disease and only 17% of non-referred patients received counselling on disease. More doctors (54% average) than nurses (16%) and other categories (7%) were reported to discuss patient's disease with them.

4.7.4. Integration of Care

The proportion of those referred for other services was very low (27%) and largely to palliative care team with poor referral to other members of multidisciplinary health team (e.g. only 7% was referred other members of multidisciplinary team, and 3 % to social workers and in spite of high proportion of patients reporting financial problems).

4.8. Conclusion

Due to the small sample it was not easy to statistically determine the palliative care effectiveness within this group. There was however significant differences in the care provided between the referred and the not referred group with regard to pain and symptom management, psychosocial care and of the integration of care.

CHAPTER 5

DISCUSSION, CONCLUSION AND RECOMMENDATIONS

5.1 Introduction

South Africa is currently implementing the Operational Plan for Comprehensive HIV/AIDS Care, Management and Treatment (CCMT) developed in 2003(DOH, 2003). Palliative care for PLHIV is an inherent component of this plan. Further the country is midterm for the implementation of its national HIV/AIDS and STI Strategic Plan 2007-2011(NSP). The latter document has, as one of its goals, “*to provide an appropriate package of treatment, care and support services to 80% of PLHIV and their families by 2011*”. For the realization of this goal, NSP identifies several objectives and interventions, one of which is the objective to: “*enable PLHIV to lead healthy and productive lives*” by means of increased coverage of CCMT and a health system strengthening to remove the barriers for access. These strategies, goals and objectives have to be realized against the constraints of the increasing burden of the HIV disease within the country. It is therefore essential to assess the current hospital-based palliative care programmes to determine the extent of its coverage for PLHIV, in order to address the challenges that impede the provision of comprehensive palliative care as a component of CCMT.

5.2. Discussions

Table 1and Figure 1 presents the demographic information of the study population. The mean age of the study population was 36 years, ranging from 21 to 57 years old, and about 47% were in the age group 30-39 years. The age distribution in this study is

consistent with the Antenatal Survey (DOH, 2008) and HSRC Prevalence Study 2008 (DOH 2008) indicating increasing HIV prevalence in ANC attendees age 15 –49 and HIV prevalence in adults 15-49 respectively. The www.aids.org. further reported that in 2005 the national HIV prevalence by age was peaking in the age group 20-39 years old. The finding further supports South Africa's definition of the most at risk group as being women, adolescents and young adults. (DOH, 2007).

70% of respondents were females. Whilst the gender-related findings in this study are consistent with other literature on HIV prevalence among women and its linkage to their physiological vulnerability (www.aids.org; DOH,2007), there is a limitation in generalising the findings in this study since the sampling was convenient, and the study setting assigns admissions to the medical wards along gender lines. The sampling process did not consider proportionate gender representation.

37% were single and 30 % not married and cohabiting with regular partners. This finding may have implications for future planning, to avoid estate and orphan care challenges in the event of death of a single parent, with or without a co-habiting partner. Attempts to obtain literature that explicitly links marital status to HIV transmission were futile, however the risk in single persons may be increased by the corresponding risk of multiple sexual partnerships, which might be concurrent or serial in nature.(www.aids.org; DOH,2007; DOH,2009)

5.2.1. Proportion of PLHIV under palliative care programme

27% of participants were under the palliative care programme. This implies that 73% of PLHIV had no access to the palliative care programme, and thus were denied this essential service for unknown reasons. This has implications for further research to determine the reasons or barriers to comprehensive palliative care services in those hospitals where such a programme exists.

During this study, the reason given informally for the low proportion of available patients referred to the palliative care team was that only those patients requiring home-based care (stabilised, home-bound, seriously ill patients) were referred for the programme, as a result the bulk of the palliative care service was reported to be implemented in the community (community-based palliative care). In one medical ward it was reported that those requiring palliative care are referred just before discharge from hospital so that the team can follow them up in the community. The situation at the time of the study was that few hospitalised patients were accessing hospital-based palliative care, and that the same hospital palliative care team members were to follow-up patients in community-based palliative care. By implication palliative care is offered mainly in community settings and offered to terminally ill homebound patients. The following questions need be answered through further research:

- Is there a need to develop the criteria for enrolling PLHIV into the palliative care programme?
- At what stage of the HIV disease trajectory should the palliative care services be offered?
- What is the ideal model for the South African situation that will best benefit the PLHIV and family?

Answers to the above questions may further shed light as to why nationally, there is a mere 7% of sub-districts having any form of facilities for palliative care as compared to the DOH target of 100% (DOH, 2009).

5.2.2. Common palliative care needs of PLHIV

5.2.2.1. Physical symptoms

Figure 2 displays the frequency of physical symptoms reported by each PLHIV.

i. Pain

77% of respondents reported experiencing pain. According to several authors (Browde, 2001; Selwyn, 2008, Uwimana & Struthers, 2007)), pain is one of the leading physical symptoms experienced by PLHIV, yet the most under-diagnosed and under-treated symptom. The PLHIV may experience various types of pain, namely somatic, neuropathic and/or bone pain each responding to different types of analgesics such as opioids, NSAIDS or adjuvant analgesics (Faull, Carter &Woof, 2000) . These various sources of pain in PLHIV were not examined for the purpose of this study.

ii. Cough

43% of respondents reported cough as the most troublesome symptom. This study may confirm the findings in some literature of the close relationship between Tuberculosis and HIV infection (Bradshaw,Dorrington,MacPhail&Pettifor, 2004; DOH, 2006). Other opportunistic chest infections like bacterial pneumonia, PCP and disseminated Karposis sarcoma may be the source of the cough symptom. It

was however not the purpose of this study to determine the medical cause for the cough symptom.

iii. Breathlessness

30% of the respondents cited breathlessness as the most common symptom affecting their health. This symptom may be linked to the cough symptom above, or may develop without coughing due to other HIV related OI's.

iv. Diarrhoea, nausea and vomiting

23 % of respondents reported experiencing diarrhoea as well as nausea and vomiting. These may be linked to the effect of the HIV infection on the gastrointestinal mucous membrane which emphasizes the need for food safety and food security as components of the palliative care programme, and may further challenge policy makers to explain what the term “nutritional support” actually means within the CCMT context.

v. Loss of appetite

This symptom and others such as fatigue, skin itch were reported by a handful of respondents (range 3%; 13% and 17%).

There was no significant difference between the number of symptoms presented by patients and the referral pattern ($p=0.691$). Overall, a total of twenty five (83%) patients had less than three symptoms affecting their health. Only five (17%) patients had 4 or more symptoms. A thirty eight year old female widow presented

(6) six symptoms which were, pain, diarrhoea, nausea and vomiting, difficulty in swallowing and other symptoms.

The findings in this study support the importance of symptom diagnosis and symptom management which are scarce skills that the health professionals should acquire. This is particularly very important considering the fact that 76% of the respondents never reported their physical problems to health professionals, and when they do the tendency was to report to the doctor even though nurses spend most of the time with patients. Health professionals should be able to conduct comprehensive assessments of PLHIV symptoms and design a patient-centred management plan for the identified symptoms. The frequency of breathlessness and cough may suggest the close relationship between HIV and Tuberculosis, highlighting the importance of infection control as part of the palliative care package.

5.2.2.2. Psychosocial problems

Another question that was posed to the patients was to talk about the psychosocial problems they were experiencing. 7(23%) of the patients said they have never experienced any social problems. For those who were experiencing social problems, the results of the study indicated that: financial status (67%) and family relationships (37%) were the most common problems experienced by PLHIV. About 63% have experienced 1 or 2 social problems (Table 2). These findings are consistent with other studies (Uwimama & Struthers, 2007). The DOH (2007) indicates that there is a clear correlation between poverty and high HIV prevalence in South Africa.

i. Financial Problems

Financial problems were the most frequently reported problem. Majority of PLHIV relied on parents, siblings or sexual partners for income, and 30% were dependant on government disability grants. This finding supports the literature that links HIV infection to poverty (DOH, 2007; DOH: 2003), and as a result financial support is one of the serious needs for PLHIV (Harding and Higgison, 2005; Uwimana & Struthers, 2007). Some authors describe the link between psychosocial suffering and the level of pain perception by the patient (Browde, 2001; Gwyther & Cohen, 2008). This study found both financial status and pain as the key problems for the PLHI, and may suggest that the distress related to finances may contribute to the expressed feeling of pain.

The financial need may be closely linked to the need for nutritional support as pronounced in the CCMT document.

ii. Family relationships

Family relations were reported by 37% of participants. Family relationships are usually strained in an environment of fear, stigma and discrimination, for both the PLHIV and those caring for them, and may affect the whole family (WHO: 2009). This problem may impede effective implementation of the palliative care service, which is focusing on quality of life for PLHIV and their families. Palliative care is described as a total care that places the family at the centre of the interdisciplinary palliative care team. This finding may influence the last two problems, namely:

- iii. Children and home environment.
- iv. Shelter and place of stay

In this study, children, home environment, shelter and place to stay affected participants to a minimal extent, and may be attributed to the fact that most participants were residing in Gauteng, with their families and significant others.

A very low proportion of patients reported these problems to ward staff whilst a higher proportion reported these to palliative care nurses. Given the low proportion of patients referred for palliative care this indicates limited access of HIV/AIDS patients to comprehensive care and available resources.

5.2.3. Comparison of the frequency of met and unmet needs for PLHIV under palliative care programme compared to those of PLHIV not under the palliative care programme

This section sought to compare the extent to which physical and psychosocial problems reported by PLHIV above were being met or unmet in both categories of patients.

5.2.3.1. Symptom management

Comparison in symptom management was done in relation to the following factors:

- Adequacy of treatment received for symptoms in relation to the symptom relief.
- Attitude of health professionals towards complaints of physical distress raised by PLHIV

i. Adequacy of treatment

Respondents under the palliative care programme reported that they received adequate treatment for their symptoms from both nurses and doctors (62% and 71% respectively). Only 12% of their counterparts (not under palliative care) reported adequate treatment for their symptoms from nurses, and 50% of them reported adequate treatment from doctors.

The common factor in both groups was that the rating of treatment from doctors was more adequate than that of the nurses. This is a cause for concern given the fact that palliative care is a nurse driven service.

ii. Attitude of staff when complaints of symptoms are raised by PLHIV

75% of Patients under palliative care reported the attitude of nurses as caring, whilst 50% of those not under palliative care perceived nurses attitudes as caring. 88% of PLHIV under palliative care reported doctors attitude as caring, whilst 76% of their counterparts rated attitude of the doctors as caring.

There key difference here is that those PLHIV under the palliative care programme rated the attitude of both doctors and nurses as equally caring, whilst those not under palliative care rated doctors attitude as more caring than those of the nurses.

These findings imply existence of gaps in terms of distributive justice. The palliative care needs of PLHIV are not equitably addressed, and access to required care depends on whether the PLHIV is under a palliative care programme or not. The challenge for the hospital is to ensure that PLHIV receive essential care irrespective of whether they

are under a palliative care programme or not. Mechanism and models to expand the palliative care approach into generic medical care should be explored.

5.2.3.2. Pain Management

Table 4 presents management of pain by health care workers. The comparison in pain management was done in relation to:

- Pain assessment (as pain enquiry)
- Effectiveness of pain medication (as adequacy of pain treatment)for pain relief
- Frequency of pain medication, and its adjustment (this was to indirectly examine the constant suppression of pain and the management of break-through pain)

It was not possible to examine the source and types of pain experienced, as these would be better answered through staff interviews.

There was significant differences found between patients referred and those not referred with regard to the pain enquiry, frequency at which pain medication was given, medication being given before the experience of pain and adjustment of medication between treatments. Overall, 59% of the patients reported that health care workers were frequently asking them about their pain. .

i. Pain assessment

100% PLHIV under palliative care who complained of pain reported that they were frequently asked about pain, whilst 50% of their counterparts were also frequently asked about pain. In both categories, the person who asked them about pain the most was the doctor.

ii. Effectiveness of pain medication given

80% of PLHIV under palliative care reported the treatment received as adequate for pain relief, as opposed to 38% of their counterparts not under palliative care reporting the same experience. This implies that the majority of PLHIV are receiving pain treatment which is not adequate enough to relieve the pain they are experiencing. The same finding was reported by Browde in 2001; Selwyn in 2008; and Uwimana & Struthers in 2007.

iii. Frequency of pain medication

80% of PLHIV under palliative care against 35% of PLHIV not under palliative care reported that they received pain medication at regular intervals before experiencing pain. This implies that in the general medical wards, 65% of patients with pain symptoms are put on pain medication without consideration for the pharmacokinetics of the drug. PLHIV who have advanced HIV disease have constant pain and require regular analgesics taken at dose intervals (Faull, et al., 2000).

iv. Adjustment of pain medication

60% of PLHIV under palliative care as opposed to 36% of PLHIV not under palliative care reported that their pain medication was adjusted.

The findings in this study support those of some authors who have cited pain relief as one of the palliative care needs commonly unmet due to under diagnosis and the administration of ineffective pain medication (Browde, 2001; Selwyn, 2008; Uwimama & Struthers, 2007). Lack of training and appropriate skills among health care

professionals are cited as the common causes for inadequate palliative care being available including symptom and pain management. The WHO ladder for pain control was not adhered to.

5.2.3.3. Psychosocial care

Aspects of psychosocial care provided by health professionals were examined against health care worker responses to identified psychosocial problems, and HIV/AIDS disease counselling and information was provided as displayed in Table 5.

i. Problem reporting rate by PLHIV

Only 20% of PLHIV reported their psychosocial problems, and 67% of these reported their problems to a palliative care nurse whilst 17% reported to a ward sister. The majority of patients 76%, chose not to report their problems. This implies that the palliative care nurse is more approachable and has time for patients unlike the general medical ward sister.

The reportedly poor communication and uncaring indifferent attitude from nurses who traditionally spend most of their time with patients compared to doctors makes it unlikely that the issues could be reported by PLHIV, or identified and addressed by health professionals.

ii. Interdisciplinary team approach

HIV/AIDS patients require a high level of psychosocial support for various their problems such as social problems related to poverty, food security, family relationships

associated with the stigma attached to the disease, assistance with care of children, issues of disclosure and the need for family support for continuation of treatment and care at home.

The findings in this study indicate that family relationships and lack of finance ranked high among problems reported by the participants. Lack of financial independence and poverty is a critical factor in eroding individuals of their sense of independence and dignity.

Addressing these issues by referral to relevant agencies could promote the recovery of lost dignity and confidence. The findings however suggest that only 27% of the PLHIV were referred to other members of the interdisciplinary health team, and that was mainly social workers.

iii. Disease counselling and information provision

Examining disease counselling and information provided further revealed that family support, disclosure, continuation of treatment, care at home and future planning (such as Wills, child placement etc.) were not effectively discussed with non-referred patients by health workers. Disease counselling and information seems to have been provided for a higher proportion of PLHIV under palliative care (range 63%, 75% and 88%). This included discussing the feelings of those PLHIV on death and dying. Very few PLHIV not under palliative care were counselled and given information about the nature of their disease, or exploring aspects of death and dying (range 9%- 50%).

5.3. Conclusion

The purpose of the study was to assess the effectiveness of the Palliative Care programme for HIV/AIDS patients receiving general medical care at the Chris Hani Baragwanath Hospital. The findings of this study support the hypothesis that the care and support needs of HIV/AIDS patients are not effectively met when the palliative care programme is not integrated into general medical care. The study revealed the existence of gaps in the management of HIV/AIDS patients admitted to the Chris Hani Baragwanath medical wards. A significant proportion of these patients had no access to the hospital-based palliative care programme, and such specialised care could not be provided by the general medical personnel.

A proportion of HIV/AIDS patients accessing the hospital-based palliative care programme is just a drop in the ocean due to the small size of this team against the ever increasing numbers of HIV/AIDS patients being admitted into medical wards.

The study suggests that symptoms and pain complaints are not effectively identified and treated by health personnel. Provision of psychosocial and spiritual support is inadequate and that the quality of life for HIV/AIDS patients may be compromised for PLHIV in general. The study further suggests that the disease counselling is minimal, especially from nurses except for those patients referred to the palliative care group. The nature of the disease, what patients feel about the disease and death are almost never discussed with those patients who have not been referred whilst their counterparts may benefit from the palliative care team.

The study further assumes that non-palliative care nurses' attitude towards HIV/AIDS patients is uncompassionate and indifferent and that an interdisciplinary team approach and intersectoral collaboration is not being effectively employed for patient care.

5.4. Recommendations

The findings in this study can be addressed through the following broad areas of palliative care programme implementation:

5.4.1. Governance of the Palliative Care Programme

- National guidelines and policy for a palliative care programme for PLHIV, with details of an agreed definition for the country, when and how should the palliative care programme be implemented in the hospital, including other relevant settings, and a preferred model of palliative care provision suitable for the South African context to increase access and palliative care coverage for PLHIV.
- A monitoring and evaluation plan for a palliative care programme with clear programme indicators, and a set of palliative care indicators included in the next NSP 2012-2016 for hospitals, community settings and hospice care to assess programme coverage, available human capacity and resources, including utilization thereof.
- A committed national budget for a palliative care programme across all settings, and not just a home-based care budget.

5.4.2. Institutional capacity for palliative care provisions

- Strengthen the current in-service training for health personnel on palliative care to ensure equitable access to palliative care, provided by skilled workers within the general medical wards.
- Re-activate the post-basic curriculum for Diploma in Palliative care for professional nurses developed by the Chris Hani Baragwanath Nursing College, and registered with the South African Nursing Council. This will provide a pool of palliative care nurse specialists, to be deployed in all medical wards to facilitate prompt diagnosis and effective treatment of PLHIV's palliative care needs. This will improve equitable access to palliative care benefits irrespective of whether PLHIV are referred to a palliative care programme or not.
- Strengthen and establish well-staffed interdisciplinary hospital-based palliative care teams to provide advisory and consultancy services to ensure that patients palliative care needs are met effectively.

5.4.3. Further research in palliative care

- This study should be replicated on a larger scale, e.g. in more than one province, or several hospitals within one province to improve generalization of the findings.
- Studies involving staff interviews may answer some questions relating to staff knowledge, attitude and skills in palliative care and their contribution to equitable palliative care access.

- Qualitative study will explore some of the un-answered questions relating to patient satisfaction and perspectives.

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APPENDIX 1 - CLEARANCE LETTER



National School of Public Health

Dr R Brookman
Chief Executive Officer
Chris Hani Baragwanath Hospital

September 15th 2003

RE: Morere E Leseka MPH student, NSPH, MEDUNSA

Dear Dr Brookman

Mrs Morere Leseka is, in addition to being a staff member at CH Baragwanath, a Masters in Public Health student at the National School of Public Health, MEDUNSA. She has completed the course work for this degree and is now required to conduct and submit a research project in fulfilment of the requirements to graduate in 2004.

The title of her project is "**An evaluation of the effectiveness of the Palliative Care programme on the HIV/AIDS patients at Chris Hani Baragwanath Hospital**".

She requires institutional permission to gather her data and as her supervisor I would be grateful if you would consider her application to conduct her research project in your institution.

The National School of Public Health and the University of MEDUNSA research and Ethics Committee have cleared her proposal as, in their opinion, her study design does not impinge on the rights of intended participants in any way.

Yours sincerely

Helen A Lewis
Senior Lecturer
Dept. of Social & Behavioural Health Science
National School of Public Health
MEDUNSA
South Africa
083 326 1400

APPENDIX 2 - PERMISSION LETTER

23 Walden Lane
P.O. Mondeor
2091
2003.08.05

The Deputy Director
Chris Hani Baragwanath Hospital
Private Bag X06
P.O. Bertsham
2013

FOR ATTENTION: INSTITUTIONAL/ETHICS REVIEW COMMITTEE

Sir/Madam,

I am presently pursuing a Masters in Public Health (MPH) course with MEDUNSA University, and conducting a research in hospital-based palliative care for HIV/AIDS patient towards my dissertation. Herein is my request for permission to conduct in-depth interviews from patients admitted into Medical wards with HIV/AIDS related conditions. The purpose of the interview is to establish the extent of perceived palliative care provided to them irrespective of whether they are referred or not referred to the Hospital-based palliative care team. Permission is further requested to review hospital records (e.g. admission books; patients files) where necessary.

Enclosed please find my research proposal for the intended study and patient consent form

Hoping that my request will be considered.

I am

Morero Elizabeth Leseka



Student No 200254065

MEDUNSA



Caring is our Mission

CHRIS HANI BARAGWANATH HOSPITAL

DR. A. MANNING
ACTING CLINICAL DIRECTOR
PO BERTSHAM
2013
Tel (011) 933 8154/9154
Fax (011) 938 8161
e-mail: amanning@mweb.co.za

17th February 2004

MS ME LESEKA
MASTER OF PUBLIC HEALTH

Dear Ms. Leseke,

Re: Evaluation of Palliative Care Impact on HIV/AIDS care and support at Chris Hani Baragwanath Hospital

Approval is hereby given for you to conduct a study entitled: Evaluation of Palliative Care Impact on HIV/AIDS care and support at Chris Hani Baragwanath Hospital.

Thank you,

DR. A. MANNING
ACTING CLINICAL DIRECTOR

AM/lm



APPENDIX 3 - INFORMED CONSENT

CONSENT FORM FOR PARTICIPATION IN REAEARCH INTERVIEW

Dear Client,

I, Morero Elizabeth Leseka, herein request your participation in the planned research interview relating to health care for your disease. The information will be used for improvement of care for other people who may suffer from similar disease. You are at liberty to decline the request and your treatment will not be compromised by your refusal.

Thank you

RESEARCHER'S SIGNATURE

.....

DATE:.....

CLIENT' CONSENT TO BE INTERVIEWED

I.....herein agree to be interviewed for the purpose of research. I further agree that the nature of research has been explained to me, and I understands all the terms of my participation.

CLIENT SIGNATURE

.....

DATE:

APPENDIX 4

PATIENT INTERVIEW QUESTIONNAIRE

Study Number: NSPH/ST/2003/12

Interview No:

Date:
(dd /mm / yyyy)

Interviewer initials:

Patient Category:

Under Palliative Care

Not Under Palliative Care

1. SOCIO-DEMOGRAPHIC DETAILS

1.1. Gender (tick *one* box only)

- Male
 Female

1.2. Age in years (tick *one* relevant range only)

- 15-24
 25- 34
 35-44
 45- 54
 55 – 64
 65 and over

1.3. Marital Status

- Married

- Never married
- Divorced
- Widowed

1.4. Do you have any children?

- Yes
- No

If yes, what are their ages in years?

- < 1
- 1 -5
- 6- 10
- 10-14
- 14-18
- > 18 yrs

1.5. Do you have any dependants other than your children and/or your spouse?

- Yes
- No

1.6. What is the main source of your income? (tick *one* relevant box only)

- Own earnings
- Spouse
- Parents
- Government Grant
- Other

(specify).....

1.7. Highest level of education

- Primary School
- Secondary School
- Tertiary Education
- Other

(Specify).....

1.8. What racial group do you consider yourself?

- Black
- Coloured
- Indian
- White

1.9. Do you permanently live in Gauteng?

- Yes
- No

If no, where do you originally come from?

- Another province
- Another country

1.10. How would you classify your current place of residence in Gauteng?

- Urban
- Peri-Urban
- Rural

1.11. What type of dwelling do you live in?

- Own house
- Rented house
- Employer's room/flatlet
- Informal settlement

2. ADMISSION INFORMATION

2.1. Main reason for admission

.....
.....
.....

2.2. Admission frequency

- First time
- Recurrent

2.3. Length of stay in the ward during this admission

- <1 week
- 1-2 Weeks
- 3-4 weeks
- > 4 weeks

3. SYMPTOM MANAGEMENT

3.1. Which of the following physical problems are presently affecting you?

(Tick all that apply):

- 3.1.1. Pain
- 3.1.2. Breathlessness
- 3.1.3. Cough
- 3.1.4. Diarrhoea
- 3.1.5. Difficulty in swallowing
- 3.1.6. Loss of appetite
- 3.1.7. Nausea and Vomiting
- 3.1.8. Skin itch
- 3.1.9. Tiredness
- 3.1.10. Other

(specify).....

3.2. Who of the ward staff is frequently the first to know of your physical problem?

- Ward sister
- Palliative care nurse
- Doctor

3.3. How would you rate the care that you get from the staff for the physical problems?

- Adequate enough to relieve the problem
- Inadequate to relieve the problem
- None at all

3.4. The following staff members respond with a warm and caring attitude when you complain to them about your physical problems :

	Strongly Agree	Agree	Unsure	Disagree	Strongly disagree
3.4.1.Ward sister					
3.4.2.Palliative Care Nurse					
3.4.3.Ward doctor					

4. PAIN MANAGEMENT

4.1. How often does the staff ask you about the experience of pain?

- Frequently
 Sometimes
 Never

4.2. Who of the ward staff frequently ask you about your pain experience?

4.2.1 Ward sister

- Yes
 No

4.2.2 Palliative care nurse

- Yes
 No

4.2.3 Doctor

- Yes
 No

4.3. How often are you given the treatment for pain?

- Only when complaining of pain
 At regular intervals, already experiencing pain
 At regular intervals, before experiencing pain

4.4. How would you rate the treatment you are receiving for pain relief?

- Adequate enough to relieve the pain
- Inadequate to relieve the pain
- None at all

4.5. Was your pain medication ever increased /changed because of the pain you are experiencing in between the treatment intervals?

- Yes
- No

5. PSYCHOSOCIAL CARE

5.1. Are you currently anxious or worried about anything?

- Yes
- No

If yes, which one of the following problems are the courses of your anxiety or worry?

(Tick all that apply):

- 5.1.1. Family relationship
- 5.1.2. Partner/Spouse
- 5.1.3. Children
- 5.1.4. Financial problems
- 5.1.5. Place to stay
- 5.1.6. Other

Yes	No
Yes	No
Yes	No
Yes	No
Yes	No
Yes	No

(specify).....

5.2. Did you tell any staff member about your problem?

- Yes
- No

. If yes, who of the staff members did you feel most comfortable to tell about your problem?

- Ward sister
- Palliative care nurse
- Doctor
- Other (specify).....

If your answer is no, would you mind to briefly tell me why?

.....

.....

.....

.....

5.3. How would you rate the support you received when you tell the person about the problem?

- Adequate, and likely to resolve the problem
- Adequate, but unlikely to resolve the problem
- Inadequate, and unlikely to resolve the problem
- No support at all

5.4. Who of the staff members ever talked to you about the following aspects of your disease?

	Ward sister	Palliative care nurse	Doctor	None of them
5.4.1.Disease Aspect				
5.4.2.Nature of your disease				
5.4.3.Treatment for your disease				
5.4.4.Your feelings about the disease				
5.4.5.The need to tell somebody close about your disease				
5.4.6.That your disease has no cure				
5.4.7.That your disease is likely to shorten your life				
5.4.8.Your feelings about death and dying				
5.4.9.Future planning				

5.5. Did the ward staff talk to you about the following discharge plan?

5.5.1 Continuation of treatment after discharge

Yes

No

5.5.2 Care at home

Yes

No

5.5.3 Family support

Yes

No

6. INTEGRATION OF PATIENT CARE

6.1. In addition to the ward staff, who else do you receive the care and support from?

- 6.1.1 Family
- 6.1.2 Priest or Religious leader
- 6.1.3 Social Worker
- 6.1.4 Dietician
- 6.1.5 Counsellor
- 6.1.6 Other

Yes	No
Yes	No
Yes	No
Yes	No
Yes	No
Yes	No
Yes	No

(specify).....

6.2. Since your admission, were you ever counselled together with your family?

Yes

No

Do you have any thing that you feel I should know about the quality of the treatment, care and support you received during your stay in this hospital?

.....

.....

.....

.....

.....

.....

.....

Thank you very much for your participation and time,