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**Palliative Care: Needs and Expectations in a
HIV Care Centre**

by

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DECLARATION

I, Therese Maarschalk, hereby declare that the work on which this mini-dissertation is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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SOLI DEO GLORIA

Dedicated to all the patients at the Zaziwe Hope-for-Life Care Centre

ABSTRACT

Aim and goals

To determine the demographics and the physical, psychosocial and spiritual needs and expectations for the palliative care of a homeless community in an HIV Care Centre, located in the inner city of Johannesburg.

Introduction

South Africa is at the epicentre of the global AIDS epidemic. According to HIV Statistics South Africa (Avert, 2008) the HIV seroprevalence in Johannesburg was estimated at 14.3% in 2008. The palliative care emphasis combines dedicated antiretroviral treatment (ART), with patient-specific palliative care for advanced symptoms. In a community of homeless and illegal immigrants, a lack of concepts regarding healthcare exists, with limited and ambivalent support from society and the government. This leads to sketchy health care infrastructures that avoid established systems and lead to unforeseen morbidity and mortality.

Methods

A descriptive, analytical study was conducted with either a self-administered or interview-administered (in case of illiterate participants) questionnaire, combining the Palliative care Outcome Scale (POS) and FICA in a palliative care centre. Demographic information regarding gender, age, nationality, abode and referral to the Care Centre was obtained. Scaled questions (POS and FICA) were ticked with respect to physical, psychosocial and spiritual needs and physical and psychosocial expectations of palliative care. One open-ended question regarding complaints in the last three days was completed at the end.

Results

Ninety-eight questionnaires were completed. The majority of the respondents were female and more than half was younger than 30 years old. The majority of participants came from Gauteng in South Africa. The POS revealed little need for pain and symptom relief, but a huge expectation for pain and symptom relief, and especially for ART. The psychosocial needs, as determined by the anxiety of the patient or family were small, as were the expectations that something can be done to

these anxieties. The spiritual aspect of having a faith and the impact on the illness had a significant statistical ($p= 0.001$) correlation. The open-ended question revealed similar concerns, with painful feet (neuropathy) the prominent physical complaint. The most important psychosocial issue was assistance with obtaining a social grant or identity document and the fear of dying was the prominent spiritual component.

Conclusions

The majority of participants were females younger than 30 years old, correlating with national figures for HIV disease. However, it is of much concern that they are at an advanced stage of the disease and require palliative care. The illegal immigrants from neighbouring countries were not the majority of patients, as often perceived, which confirms that they do not utilise this specific HIV Care Centre. The needs and expectations for palliative care in this homeless community were small regarding the physical component (with expectation more than needs), huge regarding psychosocial components and significant for spiritual elements.

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GLOSSARY

AIDS	acquired immune deficiency syndrome
ART	antiretroviral therapy
FICA	F aith, I llness, C ommunity, A dress/ A ction Spiritual History
HIV	human immunodeficiency virus
KZN	Kwazulu Natal
MES	Metro Evangelical Services
PEPFAR	President's Emergency Plan for AIDS Relief
POS	P alliative care O utcome S cale
RSA	Republic of South Africa
STAS	Support Team Assessment Schedule
VCT	voluntary counselling and testing
TB	tuberculosis
UNAIDS	Joint United Nations programme on HIV/ AIDS
WHO	World Health Organization
ZAZIWE	Hope-for-Life

CHAPTER 1

INTRODUCTION

In the heart of Johannesburg, one of Africa's largest cities, is Hillbrow, the inner city suburb where approximately 800 000 people reside in less than one square kilometer. The inner city used to be a flourishing business centre and neighbourhood, but has become a poor socio-economic district characterised by crime and social problems. (Metro Evangelical Services, 2004). Many illegal immigrants from Zimbabwe, Mozambique, Nigeria and the Democratic Republic of Congo also live in Hillbrow.

The Zaziwe Hope-for-Life Care Centre is a 30-bed unit rendering palliative care to patients from the surrounding area. From a palliative care perspective, the aim is to provide symptom relief in patients' final days and attempts to allow those who have battled all their lives to die with dignity. But what does this community need in their final days? Although no needs assessment has been carried out in the Hillbrow area regarding end-of-life expectations, this study expects to add to our knowledge the effectiveness of the care we provide.

In the introduction palliative care in this community, the homeless as a community, Johannesburg and HIV disease in this population and the Metro Evangelical Services will be discussed.

1.1 Palliative Care

Palliative care is defined as '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,' (World Health Organization (WHO), 2001).

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 counselling, if indicated;
- will enhance 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.

These criteria are complex to fulfil for a homeless population living in uncertainty, with focus on food and shelter one day at a time. One major benefit of palliative care is that trained personnel bring the service to the people who need it rather than expecting patients to attend a clinic or other health care facility. Community-based and home-based care, particularly in resource-poor settings, is a recommended practice by the WHO and the African Palliative Care Association (APCA, 2004).

1.2 The Homeless

Homelessness is a worldwide phenomenon. Squatter housing remains a common means whereby urban households in South Africa gain access to shelter – an estimated 13.5 % of all households (1.06 million people) were homeless in 1998 (Olufemi, 1998). The inner city of Johannesburg has become a cosmopolitan area where urban residents of all races live and work. Because of the lack of affordable housing, overcrowding, social and racial tension and economic factors, people sleep on the streets and in any available space. Many businesses moved out to suburban areas because of crime, muggings, violence and robberies, and building basements became sleep shelters – the living place of the homeless.

There are multiple barriers to medical care for homeless people: physical, psychological and logistical. Most homeless people do not have any existing social structure and their scope of life is narrowed down to mere existence from day to day. Violence is part of their lives and obtaining food and shelter a priority placed well above medical care (Hwang, 2001).

Previous poor experience with medical providers leads to their neglect of personal health and the presenting of advanced disease and acute medical problems. Transportation to medical facilities, keeping appointments and bathing and dressing before visiting a health facility are concepts unfamiliar to their existence. As a result, homeless people tend to access health care via emergency medical departments (usually after hours) and experience a negative response from all those treating them - from the administrative staff to medical attendants. As they often do not have identity documents or a street address, which are necessary for classification-purposes before being allowed onto the health care system, they perceive that they are being victimised when not being attended to. Their experience of being unwelcome is perceived as discrimination (Wen, Hudak, & Hwang, 2007).

The Othandweni Street Children Project was established in the 1990s as a health care programme for the youth in Hillbrow following a critical need that was identified.

Street children would not be allowed on the local hospital premises as they were seen as hooligans and muggers and were therefore denied basic health care access (Metro Evangelical Services, 2004).

The most common health problems in the inner city are substance abuse-related illnesses and diseases of neglected nutrition (Raoult, Foucault, & Brouqui, 2001). Skin conditions such as scabies are accepted as the norm and medical attention is only sought once necessitated by secondary infections.

From the poor and homeless community's perspective, medical attendants' attitudes are judgemental and the health service experienced is 'worse than dogs,' according to a WHO and Worldbank report on poverty (Dying for Change, 2002). Their experiences of unwelcomeness are perceived as acts of discrimination. Illegal immigrants (refugees) fall under the same group as they form a considerable percentage of the homeless community in the inner city. The South African Constitution guarantees 'access to health care for all' as far as life-saving health care is concerned, including antiretroviral therapy. According to Section 27 (g) of the 1998 Refugees Act, a refugee is 'entitled to the same basic health services that the inhabitants of the Republic receive from time to time' (Government Gazette, 1998). In practice, however, barriers exist in the implementation as the lack of documentation (i.e. undocumented nationals) makes them vulnerable to arrest and deportation. Confusing fee structures at health care facilities and language issues, namely the lack of translators, are further barriers (Breen & Gwyther, 2009).

1.3 Johannesburg and HIV disease

The city of Johannesburg has a population of 2, 8 million people, 70% of whom live mainly in the large urban townships with low socio-economic conditions. For example, 14% of households use paraffin or candles rather than electricity, only 13% have a toilet located inside the home and the majority use communal taps for water supply (Chandra, 2002). According to the Johannesburg City Council, the goal in 2002 was to have water accessibility within 200m from each dwelling and to have less than 20 households sharing a standpipe.

In 2002, the unemployment rate was more than 50%. It is interesting to note that despite this unemployment rate, more than 49% of people living in this area own a cellular phone. According to Barro-Lee Data, the average length of formal schooling received by adults over 15 years of age in South Africa is 6.1 years (World Bank, 2008). In the central areas of Johannesburg (including Hillbrow), 80% of the population use the local government clinic as their medical facility while 13% prefer a traditional healer and only 7% use private medical care.

According to the 2007 AIDS Epidemic Update, southern Africa remains the epicentre of the global HIV epidemic, with more than three-quarters of deaths occurring globally in sub-Saharan Africa. In 2001, 350 000 deaths occurred and in 2007, 180 000 deaths. The corresponding HIV prevalence rate in 2001 was 16.9% and in 2007, 18.11%. The disturbing figure of 400 000 AIDS orphans in 2001 increased to 1 400 000 in 2007 (UNAIDS, 2008).

The Annual Antenatal Clinic HIV seroprevalence surveys conducted by the Department of Health showed an HIV prevalence in Johannesburg of 29.5% in 2001 and 30.3 % in 2007, which translates into an estimated one in three pregnant women attending public sector Antenatal Clinics (Report National HIV and Syphilis Prevalence Survey, 2006). The first national survey of Antenatal Clinic HIV seroprevalence in 1990 had an incidence of 0.8% and in 1996 an incidence of 12.2%.

In 1998, the Treatment Action Campaign was founded. This is a campaign for the rights of people living with HIV demanding access to treatment and ensuring treatment literacy. The government initiated a five-year plan to combat HIV and sexually transmitted infections (STIs) in 2000 and in 2002 Nevirapine for pregnant mothers was instituted by the South African High Court. Only in 2003, when the antenatal prevalence reached 27.9%, did the government approve a public antiretroviral treatment programme, which was commenced in 2004.

The HIV/AIDS survey has shown that women are infected at a much earlier age than men (i.e. an average difference of 10 years).

According to the iGoli 2010 HIV/AIDS Impact and Intervention Analysis (City of Johannesburg HIV/AIDS Strategy, 1999), the following factors drive the HIV epidemic:

- HIV transmission being mainly heterosexual
- High levels of other sexually transmitted infections
- Poverty and income inequality
- Lack of access to information and services
- Resistance to use of condoms
- Social norms which encourage multiple partners
- Street children
- Single hostel dwellings
- Sexual violence – rape
- Commercial sex work, including child prostitution

An epidemiological important aspect of the disease is place of residence. People living in urban informal settlements have by far the highest incidence, according to research by the Human Science Research Council (HSRC Media Briefs, 2007). According to the CEO, Dr Olive Shisana, “these results suggest poverty plays a significant role in increasing vulnerability to HIV.”

The socio-economic impact of the disease in South Africa, according to HIV Statistics South Africa (Avert, 2008), include:

- The average life expectancy in South Africa is now 54 years – without AIDS it is estimated that it would be 64. More than half of 15 year olds are not expected to reach the age of 60.
- Between 1990 and 2003 - a period during which HIV prevalence in South Africa increased from 0.8% to 27.9% - the country has dropped 35 places to

120th on the UN's global Human Development Index (HDI), (UN News Centre, 2005).

- Hospitals battle to cope with the number of HIV-related ill patients admitted for care. In 2006, the Health Economics and HIV/AIDS Research Division (HEARD) estimated that by 2007 HIV-positive patients would account for 60-70% of medical expenditure in South African hospitals (Veenstra, 2006).

According to O'Neill and Barini-Garcia (2003), “palliative care in HIV care is *complementary* care and not *alternative* care and provision should not be limited to when disease-directed therapy fails or is unavailable.” Initially, HIV care was palliative care orientated as no treatment was available. However, in the era of anti-retroviral therapy (ART) and the ability to control disease progression, there was a swing away from palliative care and there is still a perception that the advent of ART means that people will not die from AIDS-related illness and should not be referred for palliative care. In reality, comprehensive management of the disease includes both curative and palliative care and must be able to best assist those patients whose disease trajectory takes a fluctuating downward course.

Apart from medication adherence issues, other equally important factors must be addressed - namely, adequate nutrition, a safe place to live, pain and symptom relief and social grant assistance.

1.4 MES: Metro Evangelical Services

MES is a Section 21 company that has been rendering services in the inner city of Johannesburg for more than 20 years. MES is a community-based Christian organisation that initiates and facilitates activities to empower people holistically to live independent, sustainable and meaningful lives.

The core values of MES are based on Christian principles with special regard to love and care for others, being the voice of the righteous, acting with integrity and transparency and reaching out to all people, regardless of race, culture, religion, gender or sexual orientation. The activities of MES are driven by four main

strategies, which are implemented through six developmental programmes, with all the activities geared towards sustainable development of the homeless community. The main objectives of the organisation are housing, health, education, training and job creation, and care of the poor and social services

Currently, each of the six developmental programmes addresses a specific need in the community, namely:

Roly Poly Creche, a care centre for children six months to six years, assisting in intellectual and social development and school preparation.

Entuthukweni, a training and job creation programme, assessing individual development with personal and life skills programmes, including computer skills, upholstery, welding, bricklaying, secretarial, job creation and placement.

Community Care Programme involves outreach to homeless adults with a feeding programme, clothing, blankets and overnight shelters and temporary low cost accommodation. This programme assists with disasters such as fires, etc. in the Johannesburg inner city.

Joshua Youth Service & Development renders a one-year post Grade 12 volunteer programme involved in youth campaign activities with after school care, holiday camps and skills development for teenagers.

Othandweni Street Children Project focuses on street children's basic care, entrepreneurial training in shelters and family group conferences.

MES Impilo (Health) focuses on the health needs of the homeless and destitute community in the inner city and consists of primary health care through a mobile clinic, home-based care, health education and the Zaziwe Hope-for-Life Care Centre (appendix i).

1.4.1 Palliative Care Component of MES Impilo

The *Zaziwe Hope-for-Life Care Centre* for the homeless community of Hillbrow has been operational since 2003 and consists of a 30-bed facility for terminal HIV patients. It attempts to address the neglect in a geographical area where basic needs are not adequately met by institutional structures and where health care is provided by a couple of local clinics. The Hillbrow Community Hospital and the Johannesburg

General Academic Hospital for tertiary referral are less than ten kilometres away, but are utilised only for referrals of complicated palliative care cases.

In 2004, the centre became a member of the Hospice and Palliative Care Association providing services exclusively to the indigent homeless population, who are often refugees and immigrants.

In October 2005, in the context of a common vision to improve health in communities, the Aurum Institute and MES Impilo, managing the Zaziwe Care Centre, started a collaboration. The Aurum Institute is an internationally-recognised, specialist research and health systems management organisation focusing on the prevention, treatment and care of Tuberculosis (TB) and HIV. This project provides a clinic facility for the treatment and disease management of HIV for the homeless community in Hillbrow and surrounding areas. The aim is to build a sustainable model that will be able to attract continued funding and will be beneficial to both Impilo (by channelling other funds into the home-based care environment) and Aurum (by creating an opportunity for future research).

The Zaziwe Care Centre's unit consists of eight palliative care beds for patients with terminal disease, 16 beds for intermediate care and six beds (three rooms) for mothers and babies. Patients in intermediate care would include tuberculosis patients awaiting sputum culture results, patients suffering from side-effects of anti-retroviral therapy for observation or intervention and patients receiving treatment for opportunistic infections.

Two days a week the Aurum Wellness Clinic runs an outpatient clinic on the Zaziwe Care Centre's premises to determine suitability for anti-retroviral treatment. Ill and often terminally ill patients are referred to the Zaziwe Inpatient unit. Others receive counselling, laboratory investigations and enrolment onto the Aurum disease management programme, providing medication and support as part of a President's Emergency Plan for AIDS Relief (PEPFAR) partnership.

Another unique part of this development is the provision of low-cost housing through Madulomoho (a sister company of MES), where funding for six-month housing is

sponsored by Aurum, specifically for homeless people in the first six months of ART treatment. The understanding is that during this period, the identity document and associated social grant would have been organised to ensure continued payment for this accommodation. The ultimate goal is that a person previously living on the streets of Hillbrow can receive treatment through Aurum, obtain a grant, six months' accommodation and become well enough during this period to find employment and become self-sufficient to live independently. Several success stories in this regard are available (Metro Evangelical Services, 2004).

This research project aims to give insight into the needs and expectations from the community's point of view as opposed to the provider's perspective. Therefore the demographics, needs and expectations of the patients with AIDS admitted for palliative care will be determined.

In order to fulfil the WHO criteria for Palliative Care, patients' physical, psycho-social and spiritual **needs** as well as those of the relatives and their **expectations** of palliative care services requires assessment.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

The literature review will be discussed under a general palliative care section, including a literature review for HIV disease. This will be followed by literature under the headings according to the World Health Organization's (WHO) definition: physical, psychosocial and spiritual. The final section will discuss 'home and homeless' as well as 'needs and expectations' and the aim and objectives of this study will be covered.

2.2 Palliative care (general)

The World Health Organization's approach to palliative care is not linked to cancer specifically, but the need for palliative care, regardless of the disease diagnosis (Sepulveda, 2002). The Palliative Care Programme takes a comprehensive view of the problem with a public health approach integrating existing health systems, which are tailored to specific cultural and social contexts. A successful palliative care programme for resource-constrained settings requires active support from government. The ultimate goal is to provide quality care to patients and their families. The WHO has since pioneered a public health strategy to integrate palliative care into existing healthcare systems with the aim of reaching everyone in the population. Through social and collective action, 'palliative care for all' should become a reality and to be comprehensive, palliative care should be incorporated into each country's health plan, so that 'all patients living with or dying from any chronic disease may have their suffering relieved, including children and the elderly' (Stjernsward, 2007).

Palliative care is patient-centered, rather than disease-focused. The WHO has played a major role in the ongoing campaign to improve cancer pain and to make morphine more widely available. However, governmental commitment is necessary for developing a successful palliative care programme and incorporating it into existing health delivery systems (Twycross, 2002).

Uganda was the first African country to have palliative care included in its National Strategic Framework. Supported by the work of local non governmental organisations, particularly Hospice Africa Uganda, the Ministry of Health has included pain relief and palliative care in the home-care package, based on a needs assessment of patients and their caregivers. Services include essential drugs for pain and other symptom relief, food and family support. This programme was founded on a public health approach and based on the WHO National Cancer Control Guidelines (World Health Organization, 2006).

Basic day-to-day needs are more important than medical, nursing, financial, emotional or spiritual needs. Research in the rural communities in Malawi showed that only 26 % of the 86% of patients who needed food received it and less than 50% received the medical care they needed (Marum, 2000).

Karus et al. (2004) recorded a survey of self-report symptoms from three sites to compare the prevalence of symptoms. Although no clear study design was described, data collection according to similar patient reports of symptoms was done at the three centres. The results indicated that what homeless patients wanted from palliative care and what staff needed to do to take care of them, were in conflict. Although not familiar with the concept of palliative care, the patients thought that the caring team was 'great' in doing anything for them anytime it was required.

The Ottawa Inner City Health Project did a retrospective cohort study on the effectiveness of shelter-based palliative care of terminally ill homeless individuals.

Although the sample size of 28 was small, the conclusion made was that the homeless had a heavy burden of disease, including physical and psychiatric disease. Effective end-of-life care included 71% patients using continuous opiates for pain management. Compared to alternative care locations, they operated at substantial cost savings (Podymow, Turnbull, & Coyle, 2006).

Palliative care has not been reserved only for the terminal patient who is not receiving active disease orientated medication, but also ensures comprehensive care throughout the illness. With HIV disease, the possibility of a treatable opportunistic infection must always be ruled out before considering terminal care. All stages of HIV disease need palliative care and in the changing epidemiology the focus on symptom control may simultaneously need active treatment for one HIV-related condition and palliation for another (Easterbrook, 2001).

Disease-specific therapy (including ART and the treatment of opportunistic infections) and palliative care for symptoms of disease or side-effects of therapy should never be 'either-or' but rather 'both-and' (O'Neill, 2003). Possible pharmacological interactions between HIV medication, namely certain antiretrovirals, and palliative care medications, such as certain benzodiazepines and opioids, make it essential to coordinate HIV-specific and palliative care. 'The science and evidence base of palliative medicine have much to offer for improvement in quality of life, relief of suffering, enhancement of disease-specific therapy, expert end-of-life care and coping with chronic, progressive illness for patients and their loved ones' (Selwyn, 2005).

A systematic review of 34 palliative care services was done to establish whether palliative care improves the outcome of HIV. In this study, the inclusion criteria were clearly defined, but the design and sample sizes in many instances were not evaluated. Some numbers were small and not all facilities cared for HIV patients with varying outcomes and findings. The evidence largely illustrated that home palliative care and in-patient hospices significantly improved patient outcomes as far as pain, symptom control, anxiety, insight and spiritual well-being go (Harding et al. 2005).

2.3 Palliative care: physical

The need for treatment of the symptoms of HIV disease varies from symptoms of advanced disease, such as pain and organ failure, to side-effects of anti-retroviral drugs, including peripheral neuropathy and gastro-intestinal problems. The systemic review described previously (Harding et al, 2005) demonstrated that even in specialist services there was a need for improvement in pain and symptom management.

Physical symptoms of most immediate importance identified by a cross-sectional study with 64 patients from a rural home-based palliative care programme were pain, skin problems, cough, vaginal discharge and fatigue (Shawn, Campbell, Mnguni, Deflippi & Williams, 2005). A similar study investigating symptoms and sites of pain included lower limb pain (66%), mouth pain, headache, throat pain and chest pain as dominant. Other symptoms in order of prevalence were weight loss, loss of appetite, low mood, weakness, dry skin, diarrhoea, nausea and vomiting, cough and fatigue (Norval, 2004).

Pain was the dominant symptom from a report of symptoms of three palliative care programmes in the USA and, despite the availability of treatment, many HIV patients continue to experience significant physical symptoms (Karus, et al, 2004). Unfortunately, many do not perceive their symptoms as being treated.

In the Dominican Republic and Cambodia, purposive sampling was done in households of people living with HIV and an adapted Palliative care Outcome Scale (POS) was used as a measurement for validity. Pain was worse in those complaining of other chronically ill symptoms than in those not suffering from chronic illness symptoms (Pappas, Wolf, Morineau, & Harding, 2006). A limitation could be the possible generalisation of the validity findings for two different countries with different anthropological and cultural pain experiences.

Pain was the main symptom in studies regarding physical symptoms, indicating that pain is the prominent feature for consideration in palliative care.

2.4 Palliative care: psychosocial

By not only addressing physical suffering, but extending the caring aspect by investigating psychosocial and spiritual suffering, may assist a patient finding closure in their lives (Lo, Quill, & Tulsky, 1999).

In peer review articles, a patient-centered, family-involved model of care was created as an appropriate framework for understanding the value of family in end-of-life care. This is different from a disease-focused framework and fits well with social work perspectives to understand individuals in the context of their family system and greater environment (Kovacs, Bellin, & Fauri, 2006).

Sherman et al (2006) did a longitudinal pilot with the aim of testing the reliability of the McGill Quality of Life Questionnaire (MQOL). Using the MQOL (Cohen, 1995) for patients and the Quality of Life Scale (QLS) for family caregivers, patients with advanced AIDS reported a significant decreased quality of life when compared to patients with advanced cancer. It is known that the quality of life of a dying person is not determined solely by their medical care - issues such as social and emotional support, spirituality and resolving unfinished business are equally as important.

According to research, 'quality end-of-life' examined from the patient's perspective is increasingly recognised as an ethical obligation. The five areas recognised include 'receiving adequate pain and symptom management; avoiding inappropriate prolongation of dying; achieving a sense of control; relieving burden; and strengthening relationships with loved ones' (Singer, Martin, & Kelner, 1999). In Uganda, the main needs identified were control of pain relief and other symptoms, counselling and financial assistance for basic needs such as food, shelter and school fees (Kikule, 2003). Pain, lack of energy and worrying were the three major symptoms reported at three palliative care programmes in the USA (Karus, et al 2004).

Terminal care seeks to relieve symptoms such as choking and shortness of breath and to enable people to die in comfort and with dignity, in keeping with their personal wishes and religious requirements. A study in Tanzania by Kramer (1998) developed guidelines for writing a will and ensuring its legal validity to ensure that partners and children are provided for. The 'Good Death Myth' envisions an ideal death which is an acknowledged reality, organised and pain free, where the health provider's role is defined as the comforter and supporter in the dying process. Qualitative interviews done with physicians working with inner city, underserved HIV patients found all of these role expectations disappointing. Either late-stage patients refused treatment and died 'unnecessarily' or patients refused to acknowledge and accept that they were dying and subsequently died with poorly-controlled symptoms. These situations presented psychological challenges to which the physicians had to adapt (Karasz, Dyche, & Selwyn, 2003).

2.5 Palliative care: spiritual

When treating terminally ill patients, health care providers must consider the whole person and acknowledge that the spiritual dimension is an integral part of the dying process. Spiritual concerns need to be supported as much as physical and psychosocial issues to assist in recognising the purpose and meaning at the end of life (Rousseau, 2003). There has been increasing recognition and acceptance of the importance of addressing spiritual suffering as an important component of palliative care. Spiritual issues may often not be recognised by health care professionals or they may not believe they have a duty to address these issues. In a case study, Sulmasy (2006) discusses how explicit spiritual conversation with a patient might have impacted on an improved plan for care.

Although many patients derive hope from their spiritual beliefs, others may be suffering from spiritual pain. The compassion and care a doctor offers to patients is a spiritual dimension of the doctor-patient relationship. Observation in a physician study group using qualitative group discussion revealed that the physicians were concerned about their ability to communicate non-medical issues effectively as well

as manage patients' reactions and needs in the psychosocial spiritual area. The barriers identified were cultural, organisational and clinical, with communication the main concern in the clinical barrier (Chibnall, Bennett, Videen, Duckro & Miller, 2004).

A review of five medical journals to search for and identify all empirical studies including spiritual or religious results between 1994 and 1998 was conducted by Puchalski et al (2003). Only 70 of 1117 articles (6.3%) included spiritual or religious variables (Puchalski, Kilpatrick, McCullough, & Larson, 2003). In another review, only 1% of articles published in three leading journals included articles on spirituality. This emphasises the increasing importance of indicating a spiritual component in scientific research upon which to base spiritual care.

An e-mail survey to the American Board of Hospice and Palliative Medicine (AAHPM) Fellowship Directors revealed that their teaching programmes covered definitions of spirituality and religion and common spiritual issues at the end-of-life. According to this survey, spirituality training should be a major part of palliative medicine training. The main aspects of knowledge and attitudes can be taught in small group discussions, lectures and self-study (Marr, Billings, & Weissman, 2007).

A spiritual assessment form to assist health care workers was developed by Puchalski and is relevant in taking a spiritual history. This assessment aligns compassion and caregiving with the patient-doctor relationship (Puchalski, Romer, 2000). The caregiver should be aware of the beliefs and traditions of Judaism, Islam, Christianity and other faiths, and assist those not participating in formal religion to find meaning in the midst of suffering and dying (Puchalski, Dorff, & Hendi, 2004).

2.6 Home and Homeless

'Homelessness is the condition and social category of people without a regular house or dwelling because they cannot afford or are otherwise unable to maintain regular, safe, and adequate housing, or lack, regular, and adequate nighttime residence.'
(Homelessness, 2008)

Home and what it represents has different meanings to different people. Home is a concept, not a place, and a state of mind where self-definition starts. 'Going home' may indicate a wish to return to the familiar, which goes deeper than homesickness. Even in fairytales such as Grimm's 'Hansel and Gretel' and the modern Shrek movies, the need to return home in the face of incredible difficulties is illustrated. So much more the longing for 'home' when the end-of-life draws near (Marchetti-Mercer, 2006).

In a study in Uganda, where the palliative care needs of terminally ill people were identified, the preferred site-of-care was the home, although they lived in urban areas with access to health care within five kilometres of their homes (Kikule, 2003). As the sample of respondents was restricted to those registered with home-based programmes, individuals who might have chosen institutions were excluded. This could be viewed as a limitation in this study.

In research done in Toronto, a city with 30 000 homeless people, social support as a determinant of health revealed that social isolation and estrangement from families are the norm, but the street community is seen as family and supports one another as a family would (AOHC Conference, 2007).

The ultimate 'home' (after death) combines the spiritual aspect of palliative care with being called home (by God) and to wander the path to the end-of-life, befriending death (Nouwen, 2002).

2.7 Needs and Expectations

The need for palliative care, as described by the patients and not the caregivers, has been studied and compared in three projects (Karus et al, 2004). Greater differences were observed in the needs as described by the patients versus the reports of staff in the same programme. Despite the differences, a common set of medical and other services was identified, showing that 'need' is best explained as a mixture of need, demand and supply. Palliative care should include both the patient and his/her family because the need may differ. The effect of anxiety on the patient's nearest carer was

rated as the most severe current problem, while symptom control, pain control and effect of anxiety rated worse in families than patients (Higginson, Wade, & McCarthy, 1990).

Communication in terminal illness is especially important as the course of treatment may be directed by the patient's need. Patients' needs and concerns were described after interviewing terminally ill individuals and evaluating associations between patient characteristics and issues of importance. Although the 'needs' responses were disease-orientated, health care providers should be aware of the diversity of concerns among terminally ill patients. Individual assessments of needs and expectations were recommended (Kutner, Steiner, Korbett, Jahnigen, & Barton, 1999).

In the balance between Curative and Palliative Care, HIV has become another chronic and treatable, but ultimately fatal illness, as congestive heart failure or end-stage pulmonary disease. For patients, the inability to benefit from anti-retroviral treatment (ART) may be perceived as a sign of personal failure, weakness or a bad choice. On the other hand, many have to adapt to 'a second chance' at life and need psychological, emotional and economic assistance (Selwyn & Arnold, 1998).

Cochrane (2003) did a small qualitative study investigating individuals' experiences of periods of being extremely unwell followed by periods of relative well-being. This highlights the uncertainty of living with HIV and palliative care providers should be aware of this experience - the dilemma of living with a chronic disease with an unpredictable disease course.

Exploration of the concerns regarding end-of-life care in a homeless community revealed significant personal experience and feelings about death, dying and barriers to end-of-life care (Song, Bartels, Alderton, Hudson & Ahluwalia, 2007). In this qualitative study using focus groups, over fifty homeless persons were interviewed, although a limitation was potentially the monetary reward for participating.

The rationale for the study was to investigate palliative care needs of the community studied and to establish whether the palliative care offered by Zaziwe Hope for Life addressed these needs and met the expectations of the participants. In a homeless community it is a challenge to communicate the specific needs and expectations and the care is often disease-centered and not patient-centered. The different aspects of palliative care (physical, psycho-social and spiritual) will have different needs and expectations in this specific homeless community.

The research project's aim and objectives are as follows:

2.8 Aim

To determine the palliative care needs and expectations of HIV patients in a care centre for homeless people.

2.9 Objectives

- 1) To establish the demographics of the patients admitted to the care centre.
- 2) To establish their needs regarding physical, psychosocial and spiritual well-being.
- 3) To determine their expectations of physical and psychosocial care to be received.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 Introduction

The survey will be described according to the study design, the site and the participants in the research. The data were collected using an interview questionnaire requesting demographic information, palliative care information based on the Palliative Outcome Scale (POS) and FICA (Faith and Belief, Importance, Community and Address in Care) questionnaires comprising specific questions as well as an open-ended question. The data collection method and analysis will be discussed together with the ethical considerations regarding research conducted with a vulnerable population.

3.2 Study Design

This survey is a descriptive analytic study using mixed quantitative and qualitative methods. According to de Vos (2005), the dominant-less-dominant design combines quantitative and qualitative components of research (p.357). In this study design, the researcher presents a quantitative study based on needs assessment, with a small qualitative component in the last section.

3.3 Site

The Zaziwe Hope-for-Life Care Centre is situated in Jeppestown, Johannesburg. It is part of MES Impilo (the other sections being a mobile primary health clinic and home-based care services) and positioned next to Hillbrow, where other programmes of MES are conducted. The Aurum Wellness clinic operates on the same premises on Wednesdays.

3.4 Participants

The study population comprised of patients attending Zaziwe Hope-for-Life Care Centre. The first group of patients selected comprised of in-patient admissions to the Care Centre for palliative care (terminal disease or treatment for opportunistic infections) or intermediate care (those waiting for TB sputum results or management of side-effects to anti-retroviral treatment). The second group comprised of outpatients attending the Aurum Wellness Clinic as well as those referred by nearby local clinics. Outpatients visited the Aurum Wellness Clinic for assessment for suitability for anti-retroviral treatment. These patients had CD4 counts below 200, often below 50. The complications experienced by people with CD4 count less than 200 are such that the illness may be life-threatening and patients may be considered appropriate for palliative care. Patients were interviewed within the first week of admission or at their first or second visit to the Wellness Clinic. Admission criteria to the Care Centre were adhered to (Appendix ii).

3.4.1 Sampling

Purposive sampling was conducted according to the selection criteria (De Vos, 2005, p.202). All new admissions and attendees at the Wellness Clinic between September 2005 and February 2006 were invited to take part if they met the selection criteria.

Inclusion criteria for participants included the following:

- New patient to Aurum Wellness Clinic or admission to Zaziwe Hope-for-Life Care Centre
- CD4 count below 200
- Informed consent to participate

Exclusion criteria for participants included the following:

- CD4 count above 200
- Existing or previous patient of the Aurum Wellness Clinic or the Zaziwe Hope-for-Life Care Centre

- Too ill to be interviewed (comatose or obtunded)
- Obviously demented or disorientated
- Refused to consent or unable to consent to participation
- Younger than 18 years in age

Patients were given a letter explaining the nature of the research. The letter detailed the voluntary nature of participation and the opportunity to withdraw at any stage without any reprisals regarding the care or treatment they required. The trained interviewer interpreted this information on behalf of those who were not literate. The availability of the researcher (or other trained staff) for any assistance while completing the questionnaire was emphasised.

3.5 Data Collection

3.5.1 Data collection tool

Data was collected by means of an administered questionnaire consisting of demographic questions and scaled questions regarding aspects of palliative care.

The **demographic** data collected included age, gender, nationality and abode. In this mainly homeless community, research is conducted in a palliative care setting and the implication of 'home' is of specific importance. Two questions regarding address were included. In the first question, '*Where is your home?*', the reference to 'home' relates to the place of origin or birth, where relatives or family stay or where a person would refer to as a 'home place'. The second question, '*Where do you stay in Hillbrow?*' refers to the physical address in Hillbrow. As most homeless people in the inner city do not have a physical address this group was divided into those living in shelters and the true homeless, i.e. those living on the streets or under bridges. Another option was a recently developed scheme of low-cost housing, Madulomoho, and supported by the MES Aurum project. The physical addresses were divided into Hillbrow addresses or surrounding neighbourhood addresses.

Referral to the clinic, determined by the question, '*Who brought you to the clinic/care centre?*', was classified into self referral, referral by a local clinic or referral by a social worker, which included the MES Impilo Home-Based Care programme visiting people in the community. Other referral categories were the employer or family and friends.

The results of the demographic information are important to MES and the Aurum Institute in planning the services for the homeless community. The interpretation of the psychosocial part of the following questionnaire needs to be understood against the demographic background.

The **questionnaire** was adapted from the Palliative Care Outcome Scale Patient Questionnaire. (POS) (Higginson, 1997) and the FICA Spiritual History (Puchalski, 2000)

Palliative care Outcome Scale (POS)

Consent was obtained from the King's College in London to use the Palliative Care Outcome Scale (POS), a short, easy-to-use clinical outcome measure questionnaire designed to help health care workers meet people's palliative care needs. POS represents a further development in outcome measures following the Support Team Assessment Schedule (STAS) as not only does it build on the strengths of the STAS in its clinical application and ease of use, but also addresses some of the weaknesses such as integrating greater direct patient assessment.

Although the POS questionnaire consists of four components, namely the patient questionnaire, the patient score sheet, a staff questionnaire and the staff score sheet, only the patient questionnaire was used in this survey.

Adaptations to POS for this study:

Questions were included to address expectations relating specifically to symptoms and signs of HIV in the context of homelessness. The language was simplified for a

mainly illiterate community. These changes were made following detailed discussion and personal communication with the researcher's supervisor (appendix iii).

Questions were adapted to fit into categories of '*needs*' and '*expectations*' for palliative care and divided into the three fields of palliative care according to the WHO definition - *physical*, *psycho-social* and *spiritual*. The first three questions addressed the '*needs*' for '*physical palliative care*', covering aspects of:

Need for pain relief,

Need for symptom control (nausea, diarrhoea, coughing) and

Need for treatment (ART)

The '*needs*' questions were all set within a time frame: '*over the last three days*'. The subsequent three questions addressed similar aspects for '*expectations*' for palliative care (expectations related to pain relief, symptom control and treatment).

The '*needs*' for '*psychosocial palliative care*' were covered by the following two questions:

Have you been feeling anxious or worried about your illness?

Has your family or friends been worried about you?

The '*expectations*' of psychosocial care were investigated as:

Do you expect something can be done to your worries?

Do you expect someone to talk to your friends or family?

The *spiritual* component was adapted from the FICA Spiritual History by CM Puchalski using only the **F** - *Do you have a faith?* - and the **I** - *What role does your faith play in your illness?*. The **C** (community support) and **A** (address/action) were not regarded as being relevant for this questionnaire and were therefore omitted.

One open question regarding the main problems encountered during the last three days was the final question.

Validity:

Delport (De Vos, 2005, p.160) describes a valid measuring tool as ‘doing what it is intended to do, measuring what it is supposed to measure’. At the time this research was conducted, the POS had been validated in eight settings, and has since been standardised for Africa (Powell, Downing, Harding, & Mwangi-Powell, 2007). A second version of POS was developed with an amended question and a trigger added to alert the need to contact a health care practitioner. Validation, with translations into German, Spanish and Chinese, has been done in different settings, namely day-clinics, General Practitioner practices and specialist clinics. From literature reviews, the validation of POS in the Dominican Republic and Cambodia (Pappas, Wolf, Morineau & Harding, 2006) relates to this study as it dealt with people living with HIV and some terminology had to be translated to fit the culture of this specific study population.

Reliability:

According to Delport (De Vos, 2005, p.162-163), reliability has been defined as the accuracy or precision of an instrument, not with respect to what is being measured but how well it is being measured. HIL Brink defines it as ‘the consistency and stability of measurement over repeated testing periods’ (Brink, 1993).

Pilot study:

According to Strydom (De Vos, 2005, p.205-216), the pilot study is ‘standard practice in research and can be viewed as the dress rehearsal of the main investigation. The value of a pilot study is to improve the success and effectiveness of the investigation’.

The adapted POS questionnaire was piloted on a study group of 10 patients of the Zaziwe Care Centre as a test for validity and reliability. The patients were selected according to the same selection criteria. The feasibility of this study was evaluated by revisiting the goals and objectives as well as the practical implications of

interviewing on a Wednesday only. It was a training opportunity for the interviewer to familiarise himself with the process of administering the questionnaire, an opportunity to determine the time required to complete the questionnaire and a chance to test the measuring instrument.

The pilot study demonstrated that the adapted questionnaire appeared to measure the needs and expectations superficially (face validity) of the study population ensuring face validity. Content validity of measuring the full range on needs and expectations was ensured through use of previously validated tools and expert opinion in the addition of questions related to this population. No modifications were made to the questionnaire after the pilot study as no meaningful recommendations were received.

3.5.2 Data Collection Process

The questionnaire was completed anonymously and voluntarily. Patients were handed the questionnaire with the covering letter within their first week of admission or visit to the clinic. Patients who could read and write completed the questionnaire without assistance, while patients who could not read or understand English had the questionnaire administered by the MES Impilo pastor in the patient's language of choice, if possible. The total time for completion was approximately ten minutes by the individual or 20 minutes if administered by the interpreter.

Demographic data had to be filled in the blocks provided while the POS questions were answered using tick boxes. The five-point scale of the questions was easy to understand and even ill patients managed to complete it. The final open-ended question had free space for comments.

The researcher was a volunteer conducting a weekly ward round at the Zaziwe Care Centre and Wellness Clinic.

The pastor at MES Impilo agreed to act as the interviewer and was able to interpret the questionnaire. Originally from the Democratic Republic of the Congo, he has been living in Hillbrow for over 10 years and is fluent in four South African languages, namely Zulu, Xhosa, Tswana and English, as well as French and

Portuguese. He holds a masters degree in African Culture and Theology. Prior to administering the questionnaires, he was trained on the content of the questionnaire as well as the different options of answers for each question. He was specifically trained in the ethical aspects of research to obtain valid informed consent, to explain the nature of the questionnaire and, importantly, the voluntary nature of participation without compromising care received at the centre. The researcher was available on the days the questionnaires were distributed to assist with any queries. As a staff member, the pastor was already involved in the care plan of the patients and confidentiality regarding diagnosis was preserved. He explicitly agreed to maintain patient confidentiality regarding linkage to the questionnaire. Potential bias regarding the interpreter being a staff member was not considered a limitation since a single person administered all the questionnaires.

The completed questionnaires were numbered by the interviewer and handed to the researcher at the end of the day (every Wednesday). Confidentiality was ensured by complete anonymity as the participant's name did not appear on the questionnaire and storage of the completed questionnaires undertaken by the researcher and not on the premises. The interviewer kept a list of names of patients interviewed to avoid duplication and it was not possible to distinguish between questionnaires filled in by the patients and those filled in by the interviewer, apart from the differences in handwriting.

3.5.3 Data analysis

The data was processed in two categories: quantitative (demographic data and the POS questionnaire) and qualitative (the open-ended questionnaire).

The two groups were evaluated as a single group as the conditions between the two groups were very similar. It was practical to combine the two groups to get to a significant sample size.

The Medical Research Council assisted with statistical analysis using STATA (StataCorp, 2007), where quantities were sorted under categories related to the questions.

After initial evaluation, the recommendation was made to reduce the five scaling grading into three. The first and second responses and the fourth and fifth responses were grouped together. This resulted in '*no and slightly*' being combined, '*moderately*' remaining a category, and '*severely and overwhelmingly*' combined as a category. This regrouping of the categories allowed for more comprehensible presentation.

The open-ended question was processed manually and analysed thematically.

3.6 Ethical considerations

The protocol was approved by the Research Ethics Committee of the University of Cape Town. The Clearance Number is 052/2006 (appendix iv). In view of the potential ethical challenges related specifically to this research population, the researcher adhered to the national and international ethical guidelines with the following salient issues:

Informed Consent Procedure

The Informed Consent Letter, written in simplified language to ensure that all information was clearly understood, was provided to all participants. The information was explained to them in their home language using easy to understand terminology. The patients then had an opportunity to discuss the information, ask questions and an opportunity to think about the study. Once sure that they fully understood what the study entailed and agreed to participate, they could complete the questionnaire in their own time. The informed consent letter was attached to the questionnaire to ensure that all patients completing the questionnaire had read the informed consent document.

Anonymity

Due to the sensitive nature of the disease from which participants were suffering, all written questionnaires were completed anonymously and no patient could be identified by the researcher. No signature was required on the attached informed consent letter, and it was deemed that consent had been given if the questionnaire was completed.

Vulnerability

All populations should benefit from research evidence to inform medical care. Often vulnerable populations are not afforded the opportunity to take part in research for a variety of reasons. This research project encountered three forms of 'vulnerability' in the study population – namely, the homeless, the HIV population and the palliative care setting (dying population) - and explored the pressing need to identify the needs and expectations for palliative care in such a 'multi-vulnerable' population. These three groups share vulnerability through their (relative) incapability of protecting their own interests due to insufficient bargaining power and poor access to resources and are therefore easily exploited, manipulated or deceived. The study information sheet made clear that whether participating or not, it would in no way affect the treatment but would clarify their needs and expectations.

Autonomy

This would include decision-making regarding treatment, life choices, confidentiality and informed consent. At the Zaziwe Care Centre, most patients have advanced HIV disease which therefore reduces the stigma regarding the disease and HIV issues are discussed openly. Permission for this research was obtained from the management of the *Metro Evangelical Services* (Appendix v) and the Aurum Health Partnership. Informed consent was obtained from all potential participants, but each individual could choose not to take part or to withdraw at any stage without any change to the quality of care – this was repeatedly emphasised and autonomy was demonstrated by some patients who chose not to fill in the questionnaire or not to answer all the questions.

Beneficence

The intention to do good through education, treatment and research was relevant through voluntary counselling and testing (VCT) and ART adherence counselling. As indicated in the consent form, the feedback of this research will hopefully benefit the whole inner city of Johannesburg. Specific aspects and needs in palliative care identified, such as pain relief or symptom treatment, could be addressed following the patients' permission to disclose information to their clinical caregivers.

Non-maleficence

This is the obligation to minimise harm and include the risk and side-effects of treatment, stigmatisation and empowerment. Risks for patients taking part in this study could be emotional distress when confronted with critical issues or spiritual concerns. The interviewer was specifically trained to handle these and with his pastoral background he was best positioned to use these conversations for debriefing and directing discussions to a positive outcome in planning for the future. Participants were told the length of time they would need to spend on completing the questionnaire and that they would not receive any financial or material benefit from taking part. This was to ensure that no perverse incentive could be construed as a form of coercion to participate.

Justice

Justice is the obligation to distribute benefits and rights equally, including legal and social access to care. This is an important issue in the light of the past xenophobic attacks in the vicinity of the Care Centre. In the context of this research project, all eligible patients had the right to be a part of this research and to contribute and have their experience documented, regardless of their background. The homeless, people infected with HIV and people with life-threatening illness also have a right to participate in and receive the benefits of research.

Chapter 4

RESULTS

4.1 Introduction

The results of the 98 questionnaires completed between September 2006 and February 2007 will be discussed. All respondents were patients at the Zaziwe Hope-for-Life Care Centre where they had been admitted either for palliative care for terminally advanced HIV disease or for control of opportunistic infections. The other group comprised attendees to the weekly Aurum Wellness Clinic to be evaluated for anti-retroviral therapy. Usually they were not sufficiently ill to be admitted, but all had CD4 counts of below 200, even below 50. Participants from both groups were interviewed by the pastor.

Results will be discussed as one group as the responses were similar. The Medical Research Council was consulted for opinion and analysis. The recommendation following evaluation was to reduce the five scaling to three, as described in the methodology section. The demographic information, POS and FICA questionnaire results are displayed in tables and the open-ended question results are discussed and quoted.

4.2 Demographic information: **Table 1 Demographic results**

Characteristic	Total n=98	%
Age group:		
18-29 years	35	35.7
30-39 years	44	44.8
>40 years	17	17.2
Not recorded	2	2.0
Gender:		
Male	42	42.9
Female	50	51.0
Not recorded	6	6.1
Nationality:		
South Africa	81	82.7
Mozambique	2	2.0
Zimbabwe	8	8.2
Lesotho	3	3.1
Other	2	2.0
Not recorded	2	2.0
Home address:		
Gauteng	38	38.8
Eastern Cape	6	6.1
KZN	28	28.6
Mpumalanga	6	6.1
Other	20	20.4
Address in Hillbrow:		
No address	27	27.6
MES Housing	7	7.1
Shelter	14	14.3
Street address	29	29.6
Not staying in Hillbrow	20	20.4
Not stated	1	1.0
Referral:		
Family/friends	23	23.5
Local Clinic/Wellness	48	49.0
Self	14	14.3
Employer	4	4.1
Social Worker	7	7.1
Not stated	2	2.0

Age and Gender

Of the participants, 51.0% (50) were female and 42.9% (42) male. Six participants did not fill in their gender and two did not include their age. The majority of respondents (80.5%) were under the age of 40 years.

Nationality

The majority of the patients were South African citizens, i.e. 82.7% (81), followed by Zimbabwe, Mozambique and Lesotho citizens. Other countries of origin included the Democratic Republic of Congo and Nigeria.

Address: Hillbrow and Home

Gauteng was the home address for the majority of participants (38.8%), followed by 28.6% from Kwa-Zulu Natal. The remainder were from provinces in South Africa as well as neighbouring countries.

The groups of addresses were divided into overnight shelters (14.3%), low cost housing that is part of the MES Aurum scheme (7.1%), or true homeless people living under bridges or on street corners (27.6%).

A street address in Hillbrow was recorded by 29.6 % and another 20.4% lived at a street address in a neighbourhood adjacent to Hillbrow.

Referral

Patients were referred to either the Wellness Clinic or the Care Centre for admission by the employer (4.1%), a family member (23.5%), the local government clinic or the Wellness Clinic (49.0%) or a social worker (7.1%), while 14.3 % brought themselves to the clinic. Two participants did not fill in this section.

4.3 Questionnaire (POS and FICA)

The 12 questions fell into three categories, namely physical, psycho-social and spiritual. For the physical or psycho-social questions there were clear distinctions between ‘needs’ and ‘expectations,’ while the spiritual question was a direct question: *Do you have a faith?* and *What role does it play in your illness?*

The scaling had five levels from ‘*No, not at all*’ to ‘*Yes, absolutely*’ and ‘*Sometimes*’ in the middle. As described in the methodology section, this has subsequently been grouped into a three scaling for meaningful analysis.

PHYSICAL NEEDS

Three categories were used: pain, physical symptoms (nausea, diarrhoea, coughing) and treatment for HIV.

Table 2: NEEDS for PHYSICAL Palliative Care

Physical NEEDS						
Physical needs during past 3 days	No or Slightly (Occasionally)		Moderately (Sometimes)		Severely (Most of the time) or Overwhelmingly (Absolutely)	
Pain	64.58%	(62 / 96)	15.63%	(15 / 96)	19.79%	(19 / 96)
Other Symptoms	71.58%	(68 / 95)	14.74%	(14 / 95)	13.68%	(13 / 95)
Need treatment for HIV (ART)	13.48%	(12 / 89)	15.73%	(14 / 89)	70.79%	(63 / 89)

Pain

In this study, more than 64% reported minimal pain and less than 20% reported severe or overwhelming pain. Of those who reported overwhelming pain, more than 80% were in the age group 30 - 49 years.

Other symptoms (feeling sick, coughing, diarrhoea)

These results correlate with the pain-symptom scores, where more than 70% reported minimal symptoms and only 13.7% reported severe symptoms, which would probably be the reason for hospitalisation.

Severe symptoms were reported from 50% with a fixed home address in Hillbrow and only 20% of the homeless group.

Need treatment

More than 70% answered ‘*Most of the time*’ or ‘*Yes, absolutely*’ to the question considering the need for treatment for HIV.

PHYSICAL EXPECTATIONS

The same categories as for NEEDS were used.

Table 3: EXPECTATIONS for PHYSICAL Palliative Care

Physical EXPECTATIONS						
	No and Maybe, but I doubt		Maybe, I hope		Yes and Certainly	
Expect Pain Relief	6.52%	(6 / 92)	7.61%	(7 / 92)	85.87%	(79 / 92)
Expect Symptomatic Treatment	14.94%	(13 / 89)	6.90%	(6 / 89)	78.16%	(68 / 89)
Expect ART	4.44%	(4 / 90)	6.67%	(6 / 90)	88.89%	(80 / 90)

Pain relief

More than 85% of respondents replied '*Yes and certainly*' that they expected to find pain relief treatment at this facility, with less than 15% in the other categories, '*No, maybe, but I doubt*' and '*Maybe, I hope*'.

Symptom treatment

More than 78% of respondents chose '*Yes and certainly*' in their expectation of treatment for other symptoms, while the remaining 21% were divided between '*No, maybe, but I doubt*' and '*Maybe, I hope*'.

In the less than 20 year age group, all replies were positive - '*Yes, I think they can and certainly*', while in the 30 - 39 year age group 15% answered '*No and maybe*'.

Antiretroviral Treatment

Results were similar to the expectation of treatment for symptoms – 80% answered '*Yes, I think they can and certainly*' while 10 % of the 30 - 39 age group answered '*No*' to the expectation of being provided ART at this clinic.

PSYCHO-SOCIAL NEEDS:

The question addressing psycho-social needs had psychological (own worries) and social (family and friends) components.

Table 4: NEEDS for PSYCHO-SOCIAL Palliative Care

Psycho-social NEEDS						
Psycho-Social needs during past 3 days	No and Occasionally		Sometimes		Most of the time and Always	
Patient feels anxious	38.30%	(36 / 94)	32.98%	(31 / 94)	28.72%	(27 / 94)
Family feels anxious	32.29%	(31 / 96)	19.79%	(19 / 96)	47.92%	(46 / 96)

The response to the psychological component was divided almost equally in the three groups, i.e. between 28% and 38%.

The response to the social component involving friends' or families' concerns of '*Most of the time and always*' drew more than 47%, while 32% responded '*No and occasionally*'.

'*Yes, always*' was the response of 21.3% (10) of females and 12.5% (5) of males, while the majority of females, i.e. 36.2 % (17), and 31.0% (12) of males chose the option '*Sometimes*'.

Regarding the family's feelings the '*Yes, always*' option was chosen by 44.4% of the 30 - 39 age group and 28.2% of the 20 - 29 age group.

PSYCHO-SOCIAL EXPECTATIONS:**Table 5:** EXPECTATIONS for PSYCHO-SOCIAL Palliative Care

Psycho-social EXPECTATIONS						
	No and Probably not		Maybe		Possibly and Yes	
Expect something to be done to worries	24.21%	(23 / 95)	20.00%	(19 / 95)	55.79%	(53 / 95)
Expect someone to talk to family	51.58%	(49 / 95)	11.58%	(11 / 95)	36.84%	(35 / 95)

In answer to the question: *Do you expect something can be done to your worries?* more than 55% answered '*Possibly and certainly, yes*'. More than 50% did not expect someone to talk to friends or family. In this group, 54.3 % was in the age group 18 - 29 years.

SPIRITUAL NEEDS & EXPECTATIONS:**Table 6:** FAITH and ROLE of FAITH in Illness

Faith and the Role of Faith in Illness							
Faith \ Faith Role	Yes		Not Sure		No		Total
No Role or Insignificant	14.91%	(12/81)	33.34%	(2/6)	100%	(3/3)	18.89% (17/90)
Important Role	58.02%	(47/81)	50.00%	(3/6)	0.00%	(0/3)	55.56% (50/90)
Significant and Overwhelming Role	26.16%	(22/81)	16.67%	(1/6)	0.00	(0/3)	25.55% (23/90)
Total	100.00%	(81)	100.00%	(6)	100.00%	(3)	100.00% (90)

P=0.025

The question, *Do you have a faith?* had three answerable options: 'Yes', 'Not sure' or 'No'. Of all the respondents, 88.7% (86) replied that they have a faith, 8.3% (8) were not sure and 3.1% (3) said no. Of the group sure about having a faith, 90.5% (38) were male and 87.0 % (40) female and the majority of those stating not having a faith were living either in a shelter or not staying in Hillbrow.

As to what role their faith plays in illness, 55.6% (50) stated that the role was important, 25.6% (23) stated the role was overwhelming and 18.9% (17) said there was no role at all.

There was a significant ($p= 0.025$) association between faith and the role it plays. In particular, as faith increased, the role it played also increased.

4.3 Comparing NEEDS and EXPECTATIONS (research question)

Physical

Table 7: NEEDS and EXPECTATIONS for PAIN RELIEF

Needs and Expectations for Pain Relief				
Need \ Expectation	No Slightly	Moderately	Severely And Overwhelmingly	Total
No and Maybe	8.77% (5/57)	6.67% (1/15)	0.00% (0/19)	6.59% (6/91)
Maybe I hope	5.26% (3/57)	13.33% (2/15)	10.53% (2/19)	7.69% (7/91)
Yes and Certainly	85.96% (49/57)	80.00% (12/15)	89.47% (17/19)	85.71% (78/91)
Total	100.00% (57)	100.00% (15)	100.00% (19)	100.00% (91)

$p= 0.492$

The three 'need' groups did not differ significantly ($p=0.492$) with respect to their distribution over the categories of expectation. Thus, as the need increases, expectations remain similar across the group.

Table 8: NEEDS and EXPECTATIONS for SYMPTOM RELIEF

Needs and Expectations for Symptom Relief					
Need \ Expectation	No and Slightly	Moderately	Severely and Overwhelmingly	Total	
No and Maybe	15.52% (9/58)	14.29% (2/14)	15.38% (2/13)	15.29%	(13/85)
Maybe, I hope	6.90% (4/58)	0.00% (0/14)	15.38% (2/13)	7.06%	(6/85)
Yes and Certainly	77.59% (45/58)	85.71% (12/14)	69.23% (9/13)	77.65%	(66/85)
Total	100.00% (58)	100.00% (14)	100.00% (13)	100.00%	(85)

$p=0.719$

Similar to the 'pain' results', the three 'needs' groups for symptom relief do not differ significantly ($p=0.719$) with respect to their distribution over the categories of expectation.

Table 9: NEEDS and EXPECTATIONS for HIV TREATMENT

Needs and Expectations for Treatment / ART				
Need \ Expectation	No and Occasionally	Sometimes	Most of the time and Yes	Total
No and Maybe	16.67% (2/12)	0.00% (0/13)	1.69% (1/59)	3.57% (3/84)
Maybe, I hope	8.33% (1/12)	23.08% (3/13)	3.39% (2/59)	7.14% (6/84)
Yes and Certainly	75.00% (9/12)	76.92% (10/13)	94.92% (56/59)	89.29% (75/84)
Total	100.00% (12)	100.00% (13)	100.00% (59)	100.00% (84)

p=0.02

There are significant (p=0.02) differences between the 'needs' groups with respect to the distribution of expectation. In particular, the majority of 'Most of the time' patients had 'Certainly' expectations (94.92%), while the 'Sometimes' and 'Occasionally' 'needs' groups had less expectations. As need increases, so does expectation.

Psychosocial:

Table 10: NEEDS and EXPECTATIONS for PSYCHOLOGICAL PALLIATIVE CARE (as reflected in own feelings)

Needs and Expectations for Psychological Care						
Need \ Expectation	No and Occasionally	Sometimes	Most of the time and Yes	Total		
No and Probably not	29.41% (10/34)	19.35% (6/31)	22.22% (6/27)	23.91%	(22/92)	
Maybe	20.59% (7/34)	32.26% (10/31)	7.42% (2/27)	20.65%	(19/92)	
Possibly and Yes	50.00% (17/34)	48.39% (15/31)	70.37% (19/27)	55.43%	(51/92)	
Total	100.00% (34)	100.00% (31)	100.00% (27)	100.00%	(92)	

p=0.161

The three 'needs' groups do not differ significantly ($p=0.161$) with respect to their distribution over the categories of expectation, although there is a trend towards an association between this need and expectation.

Table 11: NEEDS and EXPECTATIONS for SOCIAL PALLIATIVE CARE (as reflected in family involvement)

Needs and Expectations for Social Care				
Need Expectation	No and Occasionally	Sometimes	Most of the Time and Yes	Total
No and Probably not	71.43% (20/28)	73.68% (14/19)	30.43% (14/46)	51.61% (48/93)
Maybe	7.14% (2/28)	10.53% (2/19)	15.22% (7/46)	11.83% (11/93)
Possibly and Yes	21.43% (6/28)	15.79% (3/19)	54.35% (25/46)	36.53% (34/93)
Total	100.00% (28)	100.00% (19)	100.00% (46)	100.00% (93)

p=0.001

Among the three 'needs' groups, their distribution across expectation categories were significant (p=0.001). In patients the 'No' and 'Sometimes' groups predominantly did not expect someone to talk to their family, while the greater proportion of the 'Most of the time' group had expectations in this respect.

4.4 Open-ended question:

What have been your main problems in the last three days?

Of the 98 questionnaires, 50 responded to this question. Results were divided into the three groups of symptoms, according to the WHO definition.

Physical concerns

Thirty-four of the responses related to physical problems, of which 12 (35%) involved peripheral neuropathy symptoms. Symptoms were described as ‘painful feet’, ‘pins and needles’, ‘burning feet’, ‘painful legs and knees’ A 25 year old male living in a shelter in Hillbrow wrote: *‘My only problem is just feet!’*

Gastro-intestinal complaints ranked second, with 6 (17%) responses. These varied from diarrhoea and constipation to ‘cramps in my stomach’.

Chest pain and coughing were mentioned in 5 (15%) of the responses.

Two respondents complained of tooth ache and 4 (12%) complained about loss of weight and appetite.

Single persons complained about skin rash, backache and a painful hand.

The main problem of a 25 year old female from Lesotho over the last three days was, *‘I’m feeling terribly weak,’* and a 28 year old man from Kwa-Zulu Natal wrote, *‘PAIN!!!’*

Psychosocial concerns

Thirteen of the responses related to socio-economic issues, such as financial or employment matters.

Ten (77%) related this to finding an identity document, a place to stay and a job. A 43 year old male living in a shelter wrote, *‘Place where to go when I come out.’*

An 18 year old oxygen-dependent girl’s biggest concern was *‘missing school’* and a 28year old male was worried *‘about how I could speak to my family and how they are going to take it. If I get sick who is going to look after me’.*

A 32 year old female wrote: *‘Who will take care of my children while I am here?’*

Spiritual concerns

The last three respondents were grouped under spiritual as it addressed matters such as fear of dying. A 21 year old female wrote that she was '*worried about dying*' and a 29 year old female wrote about '*too much stress, what will happen to me?*'. The last one, a 35 year old male living in MES housing stated that his biggest problems were '*anxiety, stress and clammy hands because I do not know where this disease is leading to*'.

Forty-eight respondents chose not to fill in this section.

Chapter 5

Discussion

5.1 Introduction

In July 2007, 5.7 million people in South Africa were living with HIV. Of these 3.2 million were female. By September 2007, 490 000 people were receiving anti-retroviral treatment, only 28% of those who needed treatment. More than 200 000 children are in need of anti-retroviral treatment (UNAIDS 2008). Although the South African programme is the largest programme in the world, it lags far behind what is needed to change the life-expectation of the population living with HIV. Dedicated and disease-specific palliative care for end-stage disease is more necessary than ever before, combined with ongoing anti-retroviral treatment. (Easterbrook, 2001). In this chapter the demographic results will be discussed as well as the results of the POS questionnaire. The limitations and strengths of the study will follow this discussion.

5.2 Demographics

Age and Gender

More than 80% of participants were younger than 40 years old and more than half were female. More than half of this group were younger than 30 years old. This correlates with disturbing national figures of advanced disease affecting younger females. Ninety percent of new HIV infections in South Africa are in women between the ages of 15 and 24 years old (UNAIDS 2008). The three patients between 18 and 20 years old were admitted for Palliative Care for advanced disease. Their families or relatives were not able to care for them at home due to requirements for continuous oxygen therapy or other symptom control. There were similar patients younger than 18 years who could not be included in this research as the issue regarding informed consent excluded them. This emphasizes the new population of orphaned teenagers living with advanced disease without adult supervision. A study by the South African Institute of Race Relations shows that the number of child-headed households in South Africa has increased by 25% from 118 000 in 2002 to 148 000 in 2007 (South African Institute of Race Relations, 2009)

Nationality

The majority were South Africans: most from Gauteng followed by KZN, Mpumalanga and Eastern Cape. Other countries included Zimbabwe, Mozambique and Lesotho. According to section 27 of the Constitution of RSA every person (this includes refugees and foreigners) has the right of access to health care services, including specialised care (ART and palliative care) (Government Gazette, 1998). The ongoing xenophobic discrimination in the area discourages non-South Africans to present for testing and treatment at the clinic and is a barrier to health care. The experience is that the non-South Africans are regularly found in neglected conditions under bridges and on pavements by the outreach programme of MES Impilo's Home Based Care. Non-South Africans can be admitted to the Care Centre and can be enrolled into the Aurum Institute's ART programme according to the Clinical Guidelines for Displaced Populations (South African HIV Clinician Society, 2007). These individuals do not qualify for a social grant from the South African Welfare Department. This poses a threat to the sustainability of the completeness of the MES-programme as far as upliftment of the Hillbrow community goes.

Address: Hillbrow and Home:

As the Hillbrow and the inner city population is such a migrating one it was decided to determine the address in Hillbrow as well as the home address. The importance of a 'home-address' in the palliative care setting plays a vital role. The experience at the Care Centre is that often someone longs to go 'home' when they realize they are going to die- even if they have not been there for years. 'Home' has many different meanings and is often the final rest place to end one's life journey. Home is a physical structure, a geographical location and an emotional space. According to Marchetti-Mercer (2006) 'home' and 'family' are concepts significant in the process of forming identity (both are unknown to this study population). Re-uniting people with their families is a core function of MES. As part of the holistic approach at the Zaziwe Hope-for-Life Care Centre, the social worker will do her utmost to track the family and to arrange this final journey 'home'

More than 40% of this study population lived in either a shelter or on the streets (the target for MES to 'change the heart of the city') and 30% were living at a street address in Hillbrow. Often this address was old blocks of flats, subsequently declared

unsafe for human habitation or typical houses where many people share the same house with unhygienic conditions and unreliable sanitation and electricity supply. This result is consistent with the HRSC's research correlating poverty to incidence of HIV (HSRC Media Briefs, 2007).

Referral

The majority of referrals (almost 50%) came from the Aurum Wellness Clinic which is an encouraging result as it shows the community seeks advice and utilise the testing facility regarding HIV at either the local provincial clinic or directly from the HIV clinic. The second biggest referral system was family or friends showing the community involvement in spite of the general perspective of 'homeless' without anyone caring. As in the Toronto experience, the community on the street is their own 'family', caring for one another. (AOHC Conference, 2007). A national water supplier sponsors 5 beds in the care centre with the understanding that a bed will be available for an employee needing palliative care. Multinational companies in South Africa are obliged to partake in corporate social investment (CSI) and responsibility activities to establish infrastructure and contribute to upliftment of communities. This type of initiative shows insight from corporate management to be part of holistic care for employees, not only 'teambuilding' exercises for executive managers, but providing a facility for all employees at the end-of-life.

The conclusion of the demographic information from the study population is that the majority of patients are young women, living in a variety of housing types with the majority referred from the nearby clinic.

5.3 Palliative care Outcome Scale (POS)

The needs and expectations of the different categories (physical, psycho-social and spiritual) will be discussed as a concept with some emphasis on the comparison of the needs with the expectations at the end.

Palliative care is a response to a person's physical, psycho-social and spiritual needs. In order to provide patient-centered care, the care provider has the responsibility to identify patient needs and to elicit patient choice and expectation. The compassionate

approach to combine 'need and expectation' in a holistic manner is essential to the provision of palliative care.

PHYSICAL NEEDS AND EXPECTATIONS:

Pain

Pain is a key symptom in advanced illness and pain control a measure of the success of effective palliative care. More than 64% reported minimal pain with less than 20% reporting severe pain. The **need** for pain treatment was small. Pain is often a major complaint and in the palliative care setting with emphasis on quality of life, pain relief should get the bulk of attention and focus. (Shawn, 2006 and Norval, 2004) The researcher's personal experience of the patients' pain perception differs from this result. On specific questioning the majority had some degree of neuropathic pain (HIV or TB medication related) and in some instances patients could hardly walk, but still denied suffering from 'pain'. A specific participant marked the '*no, not at all*' option, but at the open-ended question regarding main complaints in the past 3 days mentioned painful feet. Under-reporting, under-diagnosing and under-treating pain in palliative care is a much discussed topic in the field, and therefore the need for constant ongoing research (WHO Pain and Palliative Care Communication Program, 2009). The pain-experience in this population will differ from other populations as street living survival-techniques are unique and acknowledging pain may be perceived as a weakness of character. (Raoult et al, 2001).

The majority of participants, >85% **expected** pain relief even though they were not experiencing pain at present. Compared to the literature review this result correlates with findings in specialist care services (Harding, et al 2005) as well as rural programmes (Shawn et al. 2005). Seeing the effect of pain relief on other patients create the expectation of similar treatment once or when needed. This is a compliment for the Zaziwe Care Centre as a perceived treatment institute.

Other symptoms

As with 'pain', more than 71% of the participants reported no **need** for symptom relief, i.e. coughing, vomiting or diarrhoea. Once again this did not truly correlate with admission diagnoses as the most common diagnosis for admission was either diarrhoea or coughing for investigation. These results correlated with the pain-symptom score. The group with severe symptoms were 50% from a fixed home

address in Hillbrow and only 20% of the homeless group. As explained, living conditions at a home address may not be better than living on the streets. Finding shelter or food take priority above symptoms like coughing, vomiting and diarrhoea in this community and therefore only get treated once the condition is serious enough to warrant admission to a hospital or the Zaziwe Care Centre. This is typical of homeless communities around the world. (Hwang, 2001)

Although a bigger group, more than 20%, did not **expect** treatment for other symptoms (compared to the 13% who did not expect pain relief), the majority, >78% expected treatment for other physical symptoms. In the less than 30 year old age group all replies were positive, expecting symptom relief. This study population had no **need** for treatment for other symptoms, but great **expectation** for treatment. This expectation became relevant only once they were specifically asked about it, confirming that medical treatment (the need and the expectation) is not a priority in their life-style. This outcome is different from the research by Karus et al. (2004) where patients did not perceive their symptoms being treated or still suffered symptoms in spite of treatment. The homeless communities in North America may well have different needs and expectations to those in Africa. The hopelessness of homelessness gets illustrated by not expecting anything due to previous experience of unfulfilled expectations when the need was there, or to expect everything to be provided because of homelessness.

Treatment for HIV: (ART)

More than 70% answered positively to the **need** for anti-retroviral treatment. Part of the MES Impilo Homebased Care team's activity is health education and campaigns to persuade the community to know their HIV status and report for treatment. In the time these questionnaires were administered no local government clinic was equipped to roll out ART and a waiting list of up to three months existed at the academic hospitals – even to get counselling. This made the Wellness Clinic popular as patients could be put onto ART according to the Aurum/PEPFAR protocol within one month of registering. Fortunately the system has changed in the recent past and patients now get treated at a number of roll out sites in the Care Centre's immediate vicinity as well. This brings the treatment scope closer to 'both-and' and not 'either-or' for palliative care and anti-retroviral treatment (O'Neill, 2003) where the ART is

the cornerstone of therapy and symptom-directed (but patient-directed) palliative care is practised. However, it is a concern that 30% of the study population (with CD4 counts lower than 200 - often lower than 100) do not realize they need treatment.

More than 88% **expected** treatment for HIV compared to more than 70% that answered they needed it. In the epicentre of this HIV pandemic it is reassuring that the majority of participants chose to expect treatment against this disease. In this disempowered community (in many respects, particularly socially) it is encouraging that empowerment exists regarding the expectation of anti-retroviral treatment – some social justice.

PSYCHO-SOCIAL NEEDS AND EXPECTATIONS

More than 74% of males and 67% of females reported not being anxious in response to the psychological '**need**' question. Compared to the literature where 'worrying' was one of the three major symptoms (Karus, 2004) it seems as if this study population was less concerned about their own anxiety regarding their disease. Concerns regarding body weight, fatigue and skin rash are prominent during the researcher's ward rounds, but minor when compared to other concerns, such as social grants. More than 55% **expected** that something could be done regarding their worries. As the interpretation of 'worries' can be very broad and in this study population certainly associated with the assistance of obtaining a social grant, it is understandable that the majority expect this assistance. The MES Impilo social worker assists with applications for identity documents and social grants within the first weeks of admission. This is more efficient than any local clinic where this process may take months. Therefore, being admitted and having one's financial and physical problems attended to is a valid expectation. This correlates with the Ugandan study where financial support was a major need (Kikule, 2003).

Nearly half the respondents thought their family or friends were feeling anxious about them over the past three days (as the **need** for social care). 'Friends' can often be the patient in the neighbouring bed or recent acquaintances from the streets seen as family (AOHC Conference, 2007). To search for family is a fundamental part of MES activities. Often no contact was made for more than 10 years. The worry or

anxiety of the family may be more than just the ill person, but involves the place of living and other dependants. Nearly a third of males were not concerned of friends or family being worried, while over a third of women reported not being concerned. As more than half of the study population's females were younger than 30 years old, this is the typical age group where all contact with family has been lost and dependants would be toddlers and babies. HIV not only affects younger females more, but their awareness of family or friends being worried seems less than their male counterparts. The 'feminisation of poverty' refers to the increase in poverty among women. Often heading households, responsible for economical and social care of extended family members, women are seen as a vulnerable group and poverty seen as a denial of their right to equality (Sephton and Nieuwmeyer, 2009).

Sixty percent of those indicating their concern regarding the family's worries about the patient were in the over 40 year old age group. This age group would typically have dependants attending school and they would be old enough to be concerned about the ill parent. More than 50% did not expect someone to talk to friends or family. This is a reflection of the study population, mainly people without families or where the stigma of HIV isolated people from their families. As many families were very far away (even across national borders) the expectation of someone to talk to the family or relatives was not common. This corresponds with the study evaluating end-of-life care under homeless people where great ambivalence was discovered towards contacting relatives. (Song et al, 2007). When people have made the choice to separate with family (usually years ago) and be given the opportunity to re-unite towards end-of-life, it is to be expected that some would not be interested, while for others it may be important to meet family for a last time.

SPIRITUAL NEEDS and EXPECTATIONS:

The FICA question with three answerable options regarding faith (*Yes, Not sure, No*) were filled in by 97 of the participants and nearly 90 replied 'Yes'. As Metro Evangelical Services is a faith-based organisation, working in the inner city for more than 20 years, one could expect this was the 'predicted correct' answer. The second question asking the role in the illness was answered by 91 responders with over half stating the role to be '*important*'. Whether people with faith choose to utilise this service or whether the organisation responds to the desperate need in the society and

uses the opportunity to suggest core values for sustainable life changes could be debated. On the other hand, the positive response regarding their faith could have been because the pastor was the interviewer and should be regarded as biased and a possible limitation to the study. The possibility of perceived indebtedness towards MES for admission and treatment is a separate comment. The consent letter explicitly explained that there would be no compromise in care for not completing the questionnaire. No specific questions were mentioned and the possibility that patients might have perceived their treatment plan be dependant on the answer to the spiritual question can not be ruled out (despite complete anonymity). The vulnerability of the homeless, palliative care and HIV populations regarding spiritual exploitation (e.g. faith healing or herbal treatment and discontinuation of ART) is a matter for concern. This questionnaire would have been the ideal opportunity for the interviewer, a pastor, to investigate spiritual issues as suggested by Sulmasy (2006) and therefore impacting on the care plan if the anonymity was not such an important issue.

COMPARING NEEDS AND EXPECTATIONS

Although the need for **pain relief** was small, the expectation for pain treatment was big -more than 80%- even for those expressing no need for pain relief. This shows that the Zaziwe Hope for Life Care Centre is perceived to provide pain relief and other services when the need arises. The facility is regarded as a treatment centre in this specific community. The need for **symptom relief** was small, but evenly divided between those who did not need and who did need symptom relief, with the expectation for treatment high, similar to the need and expectation for pain relief. The need for **treatment for HIV** was evenly spread between those who were not sure whether they needed treatment with the larger group considering they needed treatment. As for the provision of treatment (ART) nearly all expected to receive these from the facility. The **need** for physical palliative care is small, because this population under-report or deny their symptoms, but the **expectation** to find treatment for pain, symptoms and ART at the Zaziwe Care Centre is big. In differentiating between the **psychological, social** and **spiritual** issues the comparison between the personal worries or anxiety and what could be done was insignificant. The social issues regarding the family being worried and the expectation that someone of the Care Centre will talk to them were correlating: when

the need was small, the expectation was small and when the need was bigger, so was the expectation. According to the FICA questions there was a significant association between faith and the role it plays. In particular as faith increased the role it played also increased. As discussed before, this could be due to the setting where the research was done (MES) or a significant result as far as faith and illness go.

5.4 Palliative care needs in the last three days

These results of the open-ended question were divided in the three groups of the WHO definition of palliative care. Only half completed this section of the questionnaire. Possible explanations may include physical exhaustion after completing the previous 12 questions or emotional fatigue as the previous six questions addressed psycho-social and spiritual issues.

Physical issues

Two thirds of respondents had physical complaints. As the question was specific for the last 3 days, physical complaints (with potential medical treatment) would be expected to have the greatest response. The majority had complaints regarding painful feet which are a common physical complaint in HIV (Harding, 2005) although they did not respond suffering from pain per se as discussed before. Peripheral neuropathy is a frequent presenting symptom at the Zaziwe Care Centre. Often this is HIV related, but TB-treatment also causes neuropathy. Medical (pharmacological) treatment often alleviates the symptom, although it may take time, but usually as the general condition improves on ART and TB treatment, the neuropathy subsides. The observation was that many of these respondents did not perceive the neuropathy as 'pain' as they would have answered the first POS question on experiencing pain in the previous three days as 'no' and still report in the open-ended question the concept of painful or burning or swollen feet. Whether this is a language barrier or underreporting of pain (as discussed before) remains unanswered. For people living on the street and walking wherever they need to go, even running if they need to get away from someone, painful feet will influence their basic daily living.

The following group of complaints were gastro-intestinal: diarrhoea to constipation to cramps. These symptoms probably would not differ from another population, but in this specific group, intestinal TB, Cryptosporidium, and other opportunistic infections could be the cause for these symptoms. Weight loss and poor appetite are similar symptoms typical of this study population which correlates with a study done in a neighbouring community (Norval, 2004). Although only 5 responders complained about chest pain or coughing, more than 90% of new admissions to the Care Centre get diagnosed with sputum positive pulmonary TB within the first week of admission which means they have been contagious living on the streets confirming the study by Raoult et al. (2001). The complaint about the skin rash and the painful hand may seem trivial, but were important enough to be listed as the main complaint of the past three days. Skin problems were prominent in a rural home-based programme in rural South Africa as described by Shawn et al. (2005).

Psycho-social issues

A quarter of the respondents had either psychological or social complaints. The majority had a complaint regarding an identity document or a social grant. It is known that the Zaziwe Hope-for-Life Care Centre has a fulltime social worker to assist in applying for identity documents or social grants. Multiple barriers exist to complete the documentation and affidavits for submitting these applications and for ill people it is impossible to follow this process without assistance from the social worker. For a person without an income and especially someone who has been living on the streets for years the proposition of receiving an amount of between R700.00 and R900.00 per month is understandably a major goal and therefore their occupying concern. Similar situations described as 'financial assistance' were described in Uganda (Kikule, 2003). Finding a job and a home is never-ending in this community. Unemployment due to illiteracy, lack of job opportunities, illness and competition from migrating foreigners are major reasons for poverty according to a questionnaire compiled by hospice social workers in 2007. (Sephton & Nieuwmeyer, 2009). Other issues included housing shortage, crime, debt and lack of knowledge regarding local resources. All these impact on the daily living of people and should be attended to in the package of the psychosocial palliative care.

The 18year old worried about ‘*missing school*’ deserves specific mention. Although the questionnaires were completed anonymously, it was possible for the researcher to identify this respondent from her particular focus on education. Her story illustrates the concerns and achievements possible in the palliative care setting. She was transferred from another hospice for the final months of palliative care. Her clinical diagnosis (cor pulmonale with bronchiectasis due to advanced AIDS) made her oxygen dependent and caused practical implications for her family to treat her at home due to unreliable electricity supply for her oxygen concentrator. Weighing less than 30kg and bedridden she expressed the wish to continue school. Attempts to arrange home schooling was not successful and the nearby secondary school was contacted to enquire about the possibilities of allowing her to attend school with her oxygen concentrator. Two years later (weighing 31kg) she is in grade 11 and has an oxygen concentrator at school and another at the hospice. She tells us that she wants to become a doctor.....

And there are the hidden concerns well illustrated by the 32 year old lady whose worry was expressed by ‘who would take care of my children while I am admitted’, but was actually expressing her concern regarding who will take care of the children when she is not around anymore – thereby emphasizing the need for social support in palliative care.

Spiritual issues

Although few in number, the three respondents showed clear expressions of fear for dying or the road ahead. The concept of spiritual pain could well be the underlying, unaddressed issue. (Chibnall, 2004). This is another example where the role of the pastor could be acknowledged in the crucial spiritual care in these cases if the respondents were identifiable.

5.5 LIMITATIONS OF THE STUDY

- 1) Scaling of questions: as discussed with the statistician the low response to the second and fourth option could be a language issue in the study population or the interpreter’s personal opinion. The combination of some measures gave more meaningful values.

- 2) The difference between 'needs' and 'expectations' were not clearly understood in the study population. This could be language and/or culture differences in a mainly illiterate community. This was not detected in the initial pilot study.
- 3) In the consent information letter the reassurance was given that no treatment will be compromised if people did not complete the questionnaire. This unfortunately led to basic demographic information not being completed. The missing data should have been discovered at an earlier stage if there were more regular contact sessions between the novice researcher and the supposed experienced interviewer.
- 4) Open-ended question: results would be more valuable if this was a proper qualitative interview as the answers were only a few words each time (interpreter's version and mainly illiterate community)
- 5) A number of participants could not take part due to their age being less than 18 years. This is a growing population group living with advanced disease and no parents and there is a need to address this group.
- 6) In a complete anonymous questionnaire the last open-ended question may be perceived as identifying the responder by handwriting, etc and a possible reason for omitting it. Or the illiterate patients chose not to answer this question through the interpreter.
- 7) Switching from marking a scaled option question to the question where the individual had to fill in his/her opinion could be perceived as too much effort or threatening.

5.6 STRENGTHS OF THE STUDY

As no previous need assessment has been carried out in the Hillbrow area regarding end-of-life expectations, these are valid results despite the limitations. This will be communicated to the patients and MES Management to be incorporated into protocols.

The questionnaire was accepted by all approached to do so and the willingness to partake as well as the honesty with which the questionnaires were completed was remarkable.

The MES Impilo's Zaziwe Hope-for-Life Care Centre renders holistic services regarding palliative care (physical, psycho-social and spiritual) and this is achieved with a multidisciplinary team. The importance of the different disciplines is revealed in the pastor and social worker being full-time positions and the medical doctor a part-time (with full-time nursing and health care givers). Although they do not distinguish between the different facets of palliative care provided, patients benefit from this optimal treatment.

University of Cape Town

CHAPTER 6

CONCLUSIONS AND RECOMMENDATIONS

6.1 Introduction

In this chapter the conclusion on the different aspects of the demographic information will be made as well as the conclusions reached for the objectives set for this research regarding needs and expectations for physical, psychosocial and spiritual care.

Recommendations to MESImpilo and the Aurum Institute will be discussed.

6.2 Demographics

The majority (more than 80%) of this population was younger than 40 years old and more than 50% was female. Although this fits in with national figures for HIV it is disturbing that this is also the group needing palliative care for advanced disease.

The social impact of this disease burden is huge.

The majority of responders were South African citizens with neighbouring countries represented in small numbers, Zimbabwe the most. As the Hillbrow area is infamous for its refugees and illegal immigrants, this study reveals that they do not access this facility and the home-based team need to evaluate their methods of patient-search.

Only 40% of the responders gave their home-address as Gauteng: this implies that the rest have left their home region to live in the inner city in search for a better life style and can't return to the original 'home' for various reasons.

The address in Hillbrow revealed that more than 40 % were true shelter and street-living (homeless) residents - the community MES is striving to 'change the heart of the city for'. The referral was mainly through the Aurum Wellness clinic or the local government clinic indicating the functionality of this system in the geographical area.

6.3 POS and FICA Questionnaire

The need for pain and symptom relief in this study population was small. This does not mean they have no pain, but this community revealed very little need for pain and symptom relief of their HIV symptoms. Their expectation for pain and symptom relief was very high (>80%). Although they do not experience pain, they will come to Zaziwe to get pain relief when they need it.

Regarding the need and expectation for antiretroviral treatment (ART) the result showed that more than 70% thought they needed the treatment. The concern is the 30% (all participants had CD4 counts below 200) who did not believe they need treatment. The expectation to receive treatment was close to 90% which is proof of the success of the MES-Aurum collaboration.

From the psychosocial view the participants were less worried about their own anxiety than that of their relatives or friends. They expected something can be done to their own anxiety, but did not expect someone to talk to their friends or relatives. In palliative medicine (often different from other streams in medicine) caring for needs of relatives is very important, although not expected according to this study results. A statistical significant correlation between the need and expectation regarding the family's involvement (their concerns and the expectation that someone will talk to them) was found. In a predominantly homeless community where a lot of concerns focus on acquiring a social grant, the psychosocial needs and expectations for palliative care are complex, but the reality is that these psychosocial aspects are more prominent and important than the physical aspects.

The FICA question revealed a significant association between faith and the role it plays. As MES is a faith based organization with the aim to do upliftment of the community in the inner city, this result was to be expected. The issue of perceived indebtedness was raised. Spiritual care could be better directed to incorporate the need into the care plan for the individual.

6.4 Recommendations

As discussed under the limitations of this study, the questionnaire was (even with the simplification of language) not appropriate for this population. The following recommendations to alter this will include:

- a) Different scaling options. Many African languages do not have a specific word for some of the English terminology or would have the same word for different categories (like severely and overwhelmingly). In the African POS different indicators have been implemented, but still according to a six point scale. Qualitative research as in the last open-ended question would increase the depth of information relating to this study population.
- b) Future research of the two original groups : palliative care in different settings of homelessness can be valuable in comparing those receiving care in a centre to those receiving care at home.

The recommendation to MES (and to Aurum Institute) will be to involve more social work functions in their programmes, not only applying for social grants, but providing skilled people to talk to family's relatives.

The significant correlation between the faith and the role it plays in the participants' illness emphasizes the need for spiritual accompaniment for the duration of illness.

The aim of this study was to determine the palliative care needs of this homeless HIV population. The objectives were met in establishing the demographics and needs for physical, psycho-social and spiritual well-being as well as determining their expectations for physical and psycho-social palliative care.

CHAPTER 7

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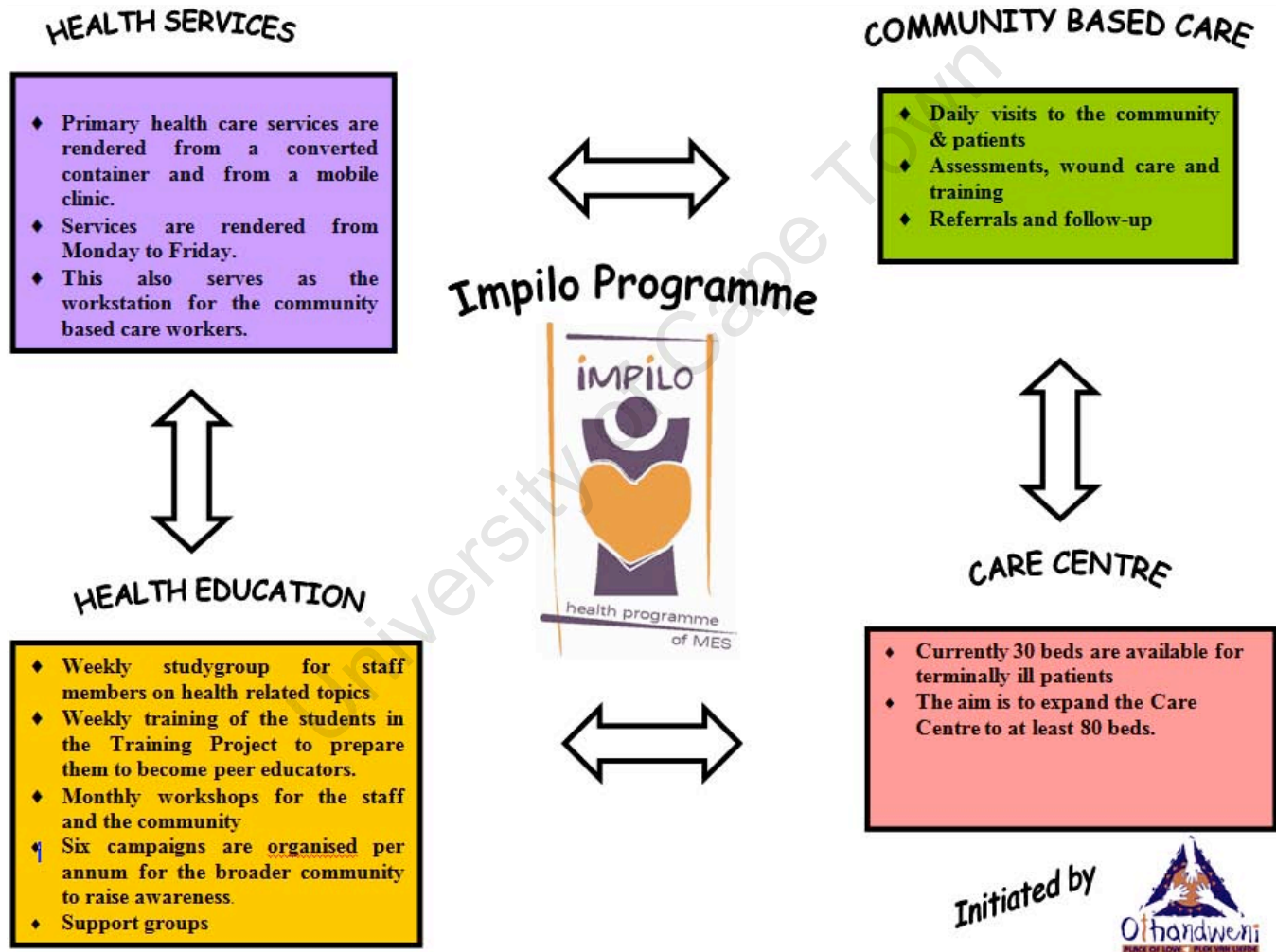
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University of Cape Town

Appendix i



Appendix ii

**REFERRAL LETTER FOR ADMISSION OF A PATIENT TO ZAZIWE
CARE CENTRE**

Telephone Number (011) 614 6629 Fax (011) 614 6624

Before admission this form with all relevant information must be faxed to Zaziwe Centre for a panel discussion.

1) Patient Information

Surname : _____

First name : _____ Gender: _____

I.D. number : _____ Age: _____

Residential address : _____

Postal Code: _____

Telephone Number : _____ Cell Number: _____

Next of Kin _____

Telephone Number: _____

2) Medical History

Reason for referral : _____

Previous History / Diagnosis _____

Test/s done : _____

(Where and when) _____

Present Medication : _____

(Date Started) _____

Previous Medication : _____

Medical Reports : PLEASE ATTACH ALL MEDICAL REPORTS

Grant : _____

(Type and amount)

3) Referred by : _____ Tel. Number : _____

Address : _____ Code: _____

Appendix iii



Private Bag X33, Hillbrow, 2038
 353 Main Street, Jeppestown
 Tel: 011-6149914 Fax: 011-6146604

Research in the Wellness Clinic

Dear Patient,

Dr Therese Maarschalk works at the Care Centre and at the Aurum Health Wellness Clinic. She is doing research as part of her studies at the University of Cape Town. We appreciate your participation in our research if you will be prepared to complete this list of questions. This will take about 10minutes of your time. Pastor Maurice will be assisting you with the translation of the questions if necessary.

You don't have to partake if you feel too ill or for whatever reason – this will not influence the treatment you will receive at our Wellness Clinic.

We don't ask your name as we don't need to know who answered what to the different questions. We do want to know how old you are, where you live in Hillbrow and where your home is.

You don't have to answer all the questions, but we will appreciate if you do!

The doctor or the matron will be around if you need to ask anything while answering the questions. Do not hesitate to ask for help.

Thank you again for your co-operation!

1. Nationality	2. Age	3. Gender
4. Where is your home?		
5. Where do you stay in Hillbrow?		
6. Who brought you to the Wellness Clinic		

Please answer the following questions by ticking in the box next to the answer that is most true for you.

1. Over the past 3 days, have you been affected by pain?

- No, not at all
- Slightly, but not bothered to be rid of it
- Moderately, pain limits some activity
- Severely, activities markedly affected
- Overwhelmingly, unable to think of anything else

2. Over the past 3 days, have other symptoms e.g. feeling sick, coughing, diarrhoea been affecting how you feel?

- No, not at all
- Slightly
- Moderately
- Severely
- Overwhelmingly

3. Over the past 3 days have you been thinking or considering you need treatment for HIV/AIDS?

- No, never
- Occasionally
- Sometimes
- Most of the time
- Yes, absolutely

4. Do you expect to find relief for your pain while here at Wellness Clinic?

- No
- Maybe, but I doubt
- Maybe, I hope
- Yes, I think they can
- Certainly

5. Do you expect treatment for your other symptoms

- No
- Maybe, but I doubt
- Maybe, I hope
- Yes, I think they can
- Certainly

6. Do you expect ART will be provided to improve your condition?

- No
- Maybe, but I doubt
- Maybe, I hope
- Yes, I think they can
- Certainly

7. Over the past 3 days have you been feeling anxious or worried about your illness?

- No
- Occasionally
- Sometimes
- Most of the time
- Yes, always

8. Over the past 3 days have any of your family or friends been anxious or worried about you?

- No
- Occasionally
- Sometimes
- Most of the time
- Yes, always

9. Do you expect something can be done to your worries?

- No
- Probably not
- Maybe
- Possibly
- Certainly yes

10. Do you expect someone to talk to your friends or family?

- No
- Probably not
- Maybe
- Possibly
- Certainly yes

11. Do you have a faith?

- Yes
- Not sure
- No

12. What role does your faith play in your illness?

- No role
- Insignificant role
- Important role
- Significant role
- Overwhelming role

13. If any, what have been your main problems in the last 3 days?

- 1)
- 2)
- 3)

UNIVERSITY OF CAPE TOWN



Health Sciences Faculty
Research Ethics Committee
 Room E52-24 Groote Schuur Hospital Old Main Building
 Observatory 7925
 Telephone (021) 406 6355 • Facsimile (021) 406 6411
 e-mail: protond@uct.ac.za

05 June 2006

REC REF: 052/2006

Dr E Gwyther
 Public Health & Family Medicine

Dear Dr Gwyther

PROJECT TITLE: PALLIATIVE CARE: NEEDS AND EXPECTATIONS IN A TERMINAL HIV/AIDS CARE CENTRE.

Thank you for submitting your study to the Research Ethics Committee for review.

Thank you for your comprehensive and thoughtful response to the committee's queries. This is an important study among a very vulnerable and largely under-researched group of patients. Your findings should benefit future management of these patients.

It is a pleasure to inform you that the Ethics Committee has **formally approved** the above-mentioned study.

This serves to confirm that the University of Cape Town Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH-GCP) and Declaration of Helsinki guidelines.

The Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines M6: Note for Guidance on Good Clinical Practice (CEMP/ICH/135/95) and E13A Code Federal Regulation Part 50, 56 and 312.

Please quote the REC REF in all your correspondence.

REC REF

Appendix v



Private Bag X33, Hillbrow, 2038
 353 Main Street, Jeppestown
 Tel: 011-6149914 Fax: 011-6146604

Dr. Maarschalk
 Dept of Family Medicine
 School of Public Health
 University of Cape Town

Dr Maarschalk

Re: Permission to interview patients for M.Phil study at UCT in the Zaziwe – Hope for Life Care Centre.

I hereby give you permission to interview patients for your research project:
 Palliative Care: Needs and Expectations in a terminal HIV/AIDS Care Centre.

Good luck with you project!!

Leona Pienaar
 Programme Manager
 30 Mar. 05

Programme of MES – Registered section 21 Company – Reg. No. 8904921 and
 Registered NPO: 023-603

Johannesburg

2010-04-30

Dear Dr,

RE: External Examiner's report: T. Maarschalk (MPhil Palliative Medicine)

Thank you for your constructive evaluation of my manuscript. After consultation with my supervisor, Dr Liz Gwyther, I am glad to inform you about the following changes:

A definition with reference for 'homelessness' has been added to the literature review.

The use of CD4 count below 200 has been clarified and explained as a measure of advanced HIV disease.

The 'final days' (mentioned twice in the manuscript) is to be seen as part of the continuum of HIV disease treated at Zaziwe: from severely or chronically ill with opportunistic infection to terminal with advanced symptoms.

Recruitment of participants was from 2 similar groups and stratification of the population for analysis was not practical. It was practical to combine the two groups to get to a significant sample size. This explanation has been added to the dissertation. (p.22)

Changes to the questionnaires took the form of adding questions relevant to the study population and was done in consultation with my supervisor to assess the homeless population's need and expectation. The existing questions would not fully address the South African scenario and specific questions testing 'expectations' were added. The questions from the original questionnaire were retained. Comment regarding face and content validity of the pilot study was added. (p.27)

A paragraph was added in the discussions chapter explaining the concept of 'needs and expectations'. This was discussed as a concept (although the results differentiated between 'needs' and 'expectations') (p.50) with specific importance to the homeless community.

The missing data and how it could have been avoided was explained and added under the limitations of the study. (p.59)

The recommendation for further study in the qualitative data of this research as well as comparing the groups of homeless participants is noted.

The focus on the intent of the study was added as a rationale on p.20

Dr Gwyther has approved these changes and the document will be submitted to the appropriate facility.

Regards

A handwritten signature in black ink, appearing to read 'Therese Maarschalk'. The signature is written in a cursive, flowing style with a long, sweeping tail on the final letter.

Dr Therese Maarschalk

Johannesburg

2010-04-30

Dear Prof Naidoo,

RE: External Examiner's report: T. Maarschalk (MPhil Palliative Medicine)

Thank you for your constructive evaluation of my manuscript. After consultation with my supervisor, Dr Liz Gwyther, I am glad to inform you about the following changes:

- a) A glossary has been added to explain the acronyms (HIV/POS/etc)
- b) The repetitive presentation of the questions in the Results chapter has all been deleted.
- c) The use of HIV/AIDS has been substituted with HIV or HIV disease unless specifically mentioned as HIV/AIDS from literature or studies originating from the time when this was a common abbreviation.
- d) The antenatal sero-prevalence for Johannesburg has been substituted to the general sero-prevalence for HIV in Johannesburg.
- e) Attention has been paid to all the suggested re-phrasing of text to clarify the meaning of concepts as in CD4 count below 200.
- f) Grammar and typographical corrections were corrected.

Dr Gwyther has approved of these changes and the document will be submitted to the appropriate facility. Thank you for the positive comment regarding being publishable which will certainly be my next goal.

Regards

A handwritten signature in black ink, appearing to read 'T. Maarschalk', with a stylized flourish at the end.

Dr Therese Maarschalk