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**The individual context and met and unmet palliative care needs of stage III and IV
HIV/AIDS isiXhosa speaking patients in the Grahamstown hospice service**

By Barbara Matthews

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DECLARATION

I, Barbara Matthews hereby declare that the work on which this dissertation/thesis 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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Abbreviations

APCA	African Palliative Care Association APCA
ARVs	Anti-retrovirals
COHSASA	Council for Health Services Accreditation of Southern Africa
CSG	Child support grant
DG	Disability grant
DOH	Department of Health
FICA	Spiritual assessment tool (FICA is an acronym for faith or beliefs, importance and influence, community, address)
FCG	Foster care grant
GH	Grahamstown Hospice
HAART	Highly active anti-retroviral therapy
HIV	Human Immunodeficiency Virus
HPCA	Hospice Palliative Care Association
ICHC	Integrated Community-Based Home Care
OAP	Old age pension
OI	Opportunistic infection
OVC	Orphans and vulnerable children
PCU	Palliative Care Unit
POS	Patient outcome scale
SQ	Structured questionnaire
SSI	Semi-structured interview
USA	United States of America
WHO	World Health Organization

Abstract

Introduction: Palliative care developed as a response to the specific needs experienced by terminally ill cancer patients and their families. The modern palliative care movement began in London in 1967 and African palliative care developed against this backdrop. The HIV pandemic has confronted African palliative care workers with new challenges to provide accessible, affordable, culturally sensitive care in resource limited settings. The domains of palliative care are well recognised and the provision of holistic patient centered care requires that the individual context of each person requiring palliative care is considered as these influenced the experience of life-threatening illness. The HIV burden in South Africa is complicated by other health care issues, poverty, and the implications of a multi-cultural, multi-racial society which add to the complexities of palliative care service provision. This study considered the individual context and palliative care needs of a group of HIV positive patients who access palliative care from Grahamstown Hospice.

Methods: This is a descriptive analytical study and data were collected from a cohort of adult stage III and IV HIV/AIDS isiXhosa speaking patients. Three data collection tools were used: a demographic data collection tool to collect data from patient records, and a structured questionnaire and a semi-structured interview. Previously validated data collection tools were used in the questionnaire and interview designs. Patient information, consent forms and questionnaires were translated into isiXhosa and consent taken and interviews conducted in isiXhosa. The interviews were translated into English. Ethics approval was obtained from the relevant organizations. A distress protocol was in place. Demographic and structured interview data were numerically analysed. Data from the self ranking and semi-structured interview were coded and a thematic analysis was carried out.

Results: Twenty-six patients completed the demographic and structured questionnaire and seven patients completed the semi-structured interview. Demographic data described socio-economic context, education and employment status, HIV and ARV

treatment and residential details. The structured questionnaire considered referrals and consultation patterns with traditional healers, and extracted data reflecting needs in the defined palliative care domains. Patients self ranked their concerns and they commented on the degree to which they had felt involved in their treatment decisions. The semi-structured interview revealed three themes – HIV meaning for amaXhosa HIV positive patients in Grahamstown, that palliative care needs were ongoing despite ARV therapy and describe patient Hospice partnership in HIV management.

Discussion: The socio-economic background of this cohort revealed them to be under significant economic pressure with universal unemployment, but families represented an important resource. Patients did not appear to position HIV within a traditional world view. Palliative care needs were ongoing despite available ARV therapy. Met needs resulted in improved health status, offered poverty relief and assistance to access welfare grants and resulted in patients feeling supported and cared for, while unmet needs contributed to distress. Some needs were ongoing, and others were not communicated effectively. Economic needs outranked other needs. Patients developed a relationship with GH which was therapeutic. Patients needed to be able to mobilize resources to cope and they did this both themselves and as a result of their partnership with Hospice. The importance of effective communication was identified. Patients also appeared to feel that they were informed and consulted. The study identified how the individual context of these patients did influence their palliative care needs and that the context in which GH operated also imposed limitations how certain needs, specifically economic, could be addressed.

“Each life is precious, and each death should have some meaning.”

Gregory Pappas¹

***“Both the lives and the deaths of people in developing countries should matter,
and we should do something about both.”***

Singer and Bowman²

CHAPTER ONE

1. INTRODUCTION

Palliative care as a practice, palliative medicine as a discipline and hospice as an organizational provider of palliative care, initially developed in response to the particular multi-dimensional needs of terminally ill cancer patients and their families. The World Health Organization (WHO) definition of palliative care states that “Palliative Care is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”.³ Palliative care is thus centered around the patient and his or her family and employs a multi-disciplinary team approach to provide holistic care that considers both the whole person/family unit and community context in which they find themselves. In this way physical, emotional, social and family, spiritual and economic needs can be addressed in a manner that respects a patient’s cultural environment and traditional and religious beliefs. Sound ethical principles of respect for persons, beneficence, non-maleficence and justice, and commitment to effective communication underpin the practice of palliative care. Against this background this study proposed to examine the individual context and palliative care needs of an isiXhosa mother-tongue speaking cohort of HIV positive patients who accessed palliative care from Grahamstown Hospice.

1.1 The development of appropriate and sustainable palliative care in Africa and South Africa

The modern palliative care and hospice movement began in the 1960’s⁴ and the growth of palliative care paralleled the development of specialized holistic interventions to alleviate the pain and suffering of dying cancer patients.⁵ Distress was recognised to be multi-dimensional and the need domains of palliative care later identified in the WHO

definition were explored and addressed to meet the needs of both patient and family. Education and research dissemination led to the establishment and development of palliative care services worldwide.⁶

It is recognised that the provision of quality palliative and end-of-life care requires that the context of individuals and communities requiring this care be considered.² This would include social and cultural considerations, health care requirements and capacity of communities and countries, as well as specific identification of individual palliative care needs and outcomes of existing interventions.

The HIV pandemic in Africa has challenged palliative care service provision to meet needs at personal and community levels in resource poor settings, and includes consideration of community development, care of orphans and vulnerable children (OVCs), day care programmes and feeding schemes.⁷ The growth of palliative care in Africa has considered both the development of appropriate and sustainable models⁸ and the provision of culturally sensitive palliative care.⁹

The challenges of providing palliative care services in Africa must consider the potential numbers who need care and relate these to available resources. In 2002 fifty seven million people died worldwide and 10.7 million in Africa¹⁰, a continent with less than one percent of the worlds palliative care services⁶. Little is known about the quality of the end-of-life care those dying in the developing world have access to, as research is focused on the developed world.¹¹ In the WHO African region patients have a life expectancy of 52 years compared to the WHO Americas region where life expectancy is 76 years.¹² There are 4025 palliative care services are in North America⁶, more than half of the total number of services worldwide. This is in contrast to only 136 palliative care services operating in Africa.¹³

By 1998 South African hospices identified that their capacity to provide care was under pressure from growing numbers of HIV positive patients.¹⁴ South Coast Hospice

responded by developing the Integrated Community-Based Home Care (ICHC) model, integrating prevention, palliative care and ARV provision, and mobilizing hospice and community resources. Research conducted in 1999 demonstrated that this model was relevant from rural to metropolitan communities and the ICHC has been adopted by the Hospice Palliative Care Association of South Africa (HPCA).¹⁵

In order for palliative care needs of HIV positive patients in South Africa to be appropriately met in the ARV era, needs must be described, patient context identified and country and community resources mobilized. It is suggested that palliative care is relevant beyond country or culture, but that provision of care will be influenced by community context and resources.¹⁶ It is important that Africa and South Africa identify how best to provide appropriate and affordable palliative care, and consider measures that address patient and service provision outcomes. This requires robust research, describing the African context, the unique challenges and available resources, to inform palliative care networks operating at all levels across the continent.

1.2 Continued research and development

While palliative care may be globally relevant, African based research remains imperative to continue to meet the needs of the HIV infected and affected in innovative and sustainable ways. This data, describing family, community and country specific context, patient needs and household resources will enable palliative care provision to address these issues in a sensitive, sustainable way. A number of other important research areas have been noted and include matters of pain and symptom control, balancing quality care with numbers who require access, monitoring and evaluation, organizational aspects, and promotion and support of palliative care.¹⁷

Research that addresses end-of-life issues should be cognisant of the cultural, religious and social context of patients living and dying in Africa.¹⁸ The most obvious difference between the developed and developing world practice and provision of palliative care is

the availability and accessibility of medical resources. It is postulated that there are other relevant issues including low levels of education, poverty, unemployment and political instability. Social, cultural and religious behaviours and practices, as they are relevant in the experience of illness, death and dying, also have to be taken into consideration when undertaking research in palliative care in the developing world.

The development of the APCA African Palliative Outcomes Scale¹⁹ offers a validated tool for the African context, and research conducted at community level that addresses needs and outcomes will contribute to objective measures of relevance. The importance of specific community level needs in providing a culturally sensitive service is not unique to Africa and a research from Australia suggests that palliative care practice and philosophy were readily embraced by an Aboriginal cohort when it was introduced in a culturally sensitive way.²⁰

1.3 Considering the effect of context on the palliative care needs of HIV positive patients and palliative care service provision

The right of each human being to experience culturally sensitive, compassionate care at the end of their life, enabling them to die with dignity, with the best symptom control possible, surrounded by the people they love and in the place they choose to be, is a core tenet of palliative care. The needs domains in palliative care were explored as the developing palliative care and hospice movement responded to the specific problems of those facing life-threatening illness.

The communication of needs is central to the development of a relationship between a patient/family and a palliative care worker and it is upon this foundation that information is shared, an assessment is made and needs are met. As in the discipline of Family Medicine, assessment draws upon the patient's agenda, including fears, expectations and experience of illness, and information gathering (history taking, clinical examination and special investigations) which makes up the health care worker's agenda.²¹ There

are a number of reliable and validated assessment tools that are used in palliative care which assist in assessment and evaluation of outcomes. This research is based on the Patient Outcomes Scale (POS) and the Spiritual Assessment Tool (FICA). The patient remains the primary informer in his or her experience of life-threatening illness, and this is different and unique for each person.

Context is defined as the “circumstances relevant to an event or fact”²². Context, those elements that are relevant to facing life-threatening disease, must be identified for patients requiring palliative care for HIV infection in Africa, and the influence of these on the needs, service provision and outcomes must be critically evaluated. For care to be patient centered it has to focus on the person not the disease they have, and a person exists within a context. Context is firstly relevant as it defines the socio-economic and family environment in which an individual experiences illness. Secondly, context defines resources that are available to the sick person as they meet the challenges associated with their illness. Finally establishing context should be part of the assessment that is used to establish patients’ needs and consists of a clinical, individual and contextual component.²¹

Africa has the highest global figures for people living with HIV and AIDS, deaths, new infections and AIDS orphans.^{23 24} It is the only region where the numbers of infected females outstrips males.²⁴ The United Nations postulates that in the worst case scenario the cumulative death rate for HIV could be 83 million with 89 million new infections by 2025.²⁵ South Africa is at the epicenter of the African pandemic.²⁴ There is evidence to suggest that HIV related malignant disease will also increase²⁶ but this is not yet evident in available national cancer statistics which are outdated.²⁷ In addition, research from developed world countries suggests that palliative care remains relevant for patients who access ARVs.²⁸ Thus health care priorities for South Africa must be expected to include significant requirements for palliative care for HIV positive individuals.

The emerging democracy in South Africa has been challenged by the demands of the HIV epidemic experienced in this country. These difficulties are noted by those who attempt to meet the needs of people and families facing HIV/AIDS, from households to government. Forty two percent of South African children live in households where neither parent is employed and almost three quarters of children living in the Eastern Cape, where this study was conducted, live in households with a monthly income of less than R800 (about US\$100).²⁹ Within this context, resource allocation for health, social welfare and education needs to be considered and health care spend has to be fairly distributed between prevention programmes, disease modifying interventions and rehabilitation. There is growing consensus that palliative care is a human right and that it should and be can be integrated into public health programmes.^{30 31}

In addition to a high HIV burden and economic challenges, South Africa is also a multi-racial, multi-lingual and multi-cultural society with differing religious and traditional belief systems. These should be recognised as relevant to needs of HIV infected patients accessing health care.

Thus physical, emotional, social and family, spiritual and economic needs of HIV positive people living in Africa and South Africa must be considered alongside the contextual circumstances in which they experience the challenges of HIV infection.

1.4 Grahamstown – context for the study

Grahamstown is a small town in the Eastern Cape region of South Africa. The total population of the Makana municipal area is approximately 74 500 with 62 000 people living in the town itself.³² The largest population group in the town is isiXhosa speaking African/Blacks.³³ Grahamstown is a well-known educational centre, the High Court of the Eastern Cape sits in the town and the area is a popular tourist venue. Despite this, the 2001 census showed that only 27% of the town's 15-65 year olds were employed.³³

Grahamstown Hospice (GH) was established in 1984 and operates as a home-based care service with professional nurses and community health workers taking care of patients in the community. A partnership with Settlers Hospital (Department of Health, Rotary and First National Bank), now also provides the town with in-patient palliative care.³⁴ GH accepts referrals from municipal clinics, private practitioners, Settlers Hospital, the Port Elizabeth Hospital Group as well as self-referrals. The inter-disciplinary team at GH consists of professional nurses, community health care workers, a social worker, a psychologist and a palliative care-trained physician. GH sees patients from all socio-economic sectors; from patients with private medical insurance to the indigent, and the service provided is free of charge to all. The work of Grahamstown Hospice has shifted over the years to include a significant number of HIV positive patients. Between January 2002 and November 2003 the HIV caseload increased by 1500%.³⁵

Settler's Hospital was established in 1922. It is a secondary level hospital of 219 beds with theatre and maternity services. The in-patient Palliative Care Unit (PCU) opened in March 2006 and now has ten adult beds, four paediatric beds and a step-down facility. There is a combined HIV ward round in the PCU once a week, attended by members of the GH team, members of the Settlers Hospital ARV clinic team, the hospital doctors, social workers, physiotherapists and dieticians. An audit of admissions to the PCU for the first three months of its operation revealed that 70% of patients had been admitted for HIV related problems.³⁴ About a third of patients had been referred from the ARV clinic and medical wards, and the remainder had been referred by Hospice.

Masonwabe (meaning "let us be happy") is Settlers Hospital's ARV clinic. This clinic was established as part of the national ARV roll-out programme in May 2004. In June 2008 there were 1329 patients in the service. The state funded ARV service is free at point of service, but Rosen et al³⁶ have shown that it is not free to patients in terms of other costs they incur to access treatment.

1.5 Motivation for this study

It has been shown that palliative care developed in response to patient needs as a holistic intervention that considers patients within a context of a family and community. It is also evident that the nature and burden of the HIV pandemic in Africa is relevant as individuals, families, communities and countries responding to the disease do so within the boundaries of their available resources, and palliative care responses should be appropriate and sustainable. The palliative care needs of patients cannot be explored without engaging with patients, asking them to identify their needs. Furthermore, investigation can explore how patients access and utilize resources, and experience outcomes of care within their communities as they live with HIV infection.

This study examined the context of a particular group of HIV infected patients and considered the relationship between context and need. The response to the interventions of a palliative care service was explored and outcomes were described against the background of patients' cultural world view, context and experience.

This research will contribute to a body of knowledge that will describe needs and context at community level, consider possible elements of culturally sensitive care and reflect on patient perceived outcomes to identify areas of future focus and study in South Africa and other communities with a similar context.

CHAPTER TWO

2. LITERATURE REVIEW

The literature review for this study was based on the following: electronic data base searches, Medline, Google scholar, and gray data (website postings). Key words used were HIV, palliative care, Africa, need\$, outcome\$, anti-retroviral, HAART, symptom\$, end-of-life, tradition\$, culture, belief, Grahamstown. (\$ indicates a truncated search.) Searches were refined within these keyword results: (palliative care, HIV, Africa), (HIV, need\$, symptom\$), (HIV, symptom\$, outcome\$), (tradition\$, culture, belief) and (Grahamstown, HIV, palliative care). Secondary references from studies that were particularly relevant were followed up and published material from authors who published frequently in the field of African palliative care was sought.

The review considered the current status of palliative care and palliative care research in Africa. It focused on patient needs and outcomes of palliative interventions and ARV therapy, for HIV positive people and their families. The parallels and differences for the developed and developing world were considered. The relevance of culturally sensitive care and country, community and individual context were examined with specific reference to South Africa. The review placed the research within the context of the town of Grahamstown and motivated for the relevance of the research project and methodology chosen in order to contribute to a body of knowledge in palliative care and service provision.

2.1 Palliative care research in Africa and considering new challenges

In May 2006 representatives of the international palliative care community, including APCA, adopted the Declaration of Venice to support the global development of palliative care research.³⁷ This declaration noted that current research and published scientific work is focused on the developed world, and highlighted the importance of research that

reflected patients' and families' needs and preferences within their context. The need for and importance of continent, cultural and community specific research in Africa is echoed by other authors.^{2 16 38 39 40} Consideration has been given to important focus areas for research. These include description of context, identification of the elements of patient needs, and outcomes of care at community level.^{16 17} Powell et al identified the tension between care and research, noting that one should inform the other.⁴⁰

The need for palliative care in Africa for those with HIV infection, cancer and other life limiting disease is considerable.^{2 17 10 41} Notwithstanding the implications for palliative care of the HIV pandemic, cancer prevalence rates are also expected to increase⁴² further motivating for the research and development of accessible, appropriate and sustainable models of care.^{16 44} Harding and Higginson¹⁶, Harding et al¹⁷ and Sepulveda et al⁴³ reviewed current service models in Africa, and found that palliative care was being provided across a wide spectrum of African countries, utilizing a variety of service models to provide palliative care. However, it is noted that resources, challenges and local attitudes to palliative care vary.

2.2 Influence of culture, traditional belief systems and family structure on patient context

The universal elements of palliative care are recognized but care must be sensitive to the religious and cultural beliefs of the people they serve.⁴⁴ Furthermore, palliative care needs may be influenced by context; in this case the patient facing life-threatening illness in Africa¹⁷ and care models must be appropriate and acceptable within a cultural context.^{17 20} The Cape Town Palliative Care Declaration⁴⁴ demonstrated commitment to this ideal for palliative care development and provision in this country. This is echoed in other developing regions of the world⁴⁵ and for minority groups in developed countries²⁰.

Culture is defined as “the total of the inherited ideas, beliefs, values and knowledge, which constitute the shared bases of social action”.⁴⁶ Culture influences how people see and experience the world; explain and experience illness, and the attitudes of people to end of life care.² The traditional developed world view of illness is within a scientific paradigm. In the developing world traditional belief systems influence how illness is viewed and the reason for illness may be more important than the diagnosis itself.⁴⁷ Death may be approached in a more pragmatic fashion and religious beliefs appear to offer more comfort than is the case in developed world.^{2 63 64}

The traditional belief system and spirituality of the amaXhosa is centered around the Deity, the benevolent presences and the malevolent spirits.⁴⁸ Christianity was inherited against this backdrop. The ancestors intercede for and protect the living, while the malevolent spirits can punish offenders. Illness is not considered to be natural and may sometimes be seen as punishment for going against cultural or social norms.⁴⁷ Harding et al's¹⁷ survey of end of life care in sub-Saharan Africa suggested that most surveyed programs reported that traditional healers play a role in local belief and practice and thus may play an important role in service provision and development.

A Medline search (tradition\$, South Africa, HIV, culture) was conducted and five articles were reviewed that considered the relationship between culture and traditional belief and HIV and AIDS in South Africa. Liddell et al⁴⁹ discussed proximate causes (how diseases are contracted) and ultimate causes (why diseases are contracted) suggesting that medical intervention is sought for proximate causes (and symptoms) and traditional healers manage ultimate causes. Peltzer et al⁵⁰ described the beliefs, knowledge and practices of traditional healers in KwaZulu Natal in terms of a proximate cause. Their study did not address the role of the traditional healers in the management of ultimate cause of HIV but highlighted some of the tensions that exist for patients and practitioners to integrate traditional beliefs systems and a medical, scientific paradigm. Other sources suggested that there are conflicting beliefs that explained proximate and ultimate causes of HIV infection, employing a biomedical explanation on one hand and

traditional belief systems on the other.^{51 52} It has also been identified that traditional beliefs are not necessarily always in conflict with those of Western medicine.⁵³ None of these studies considered the understanding and beliefs of HIV of patients who are living with HIV/AIDS and are actively accessing palliative care and ARV therapy.

Literature was reviewed to provide a description of family and household structure^{54 55 56} and to consider some of the important implications of HIV infection at the level of household structure that would be relevant to this study population living in Grahamstown^{58 59 60 61}.

Within this paternalistic, communal and familial society men are seen as the custodians of social customs.⁴⁷ Family bonds and kinship are central features of the culture of the amaXhosa⁴⁷ and African households are built around patrilineal descent and patrilineal obligation.⁵⁴

Difficulties were noted in research methodology with regard to data collection that accurately reflected household composition as rules defining household membership may be limiting.^{57 59} Despite these limitations data reviewed suggested that historical and contemporary features; cultural, social and economic, contributed to household composition.⁵⁸ Siqwana-Ndulo⁵⁵ proposed that household makeup reflected a choice that amaXhosa families made to meet their needs, rather than a process over which they have no choice. Resources are shared between individuals who share kinship based on consanguineous relationships.^{54 56}

Marriage rates have been declining in South Africa.^{58 59} As kinship is based on patrilineal rules, a child derives kinship from his father's family if his parents are married, or his mother's father if his parents are not married.⁵⁶ It has been demonstrated that fewer children can be linked to their fathers than their mothers.⁵⁹ In addition, many non-orphans do not live with either parent⁵⁹ and this supported other data that demonstrated the shared commitment to child-rearing by kin in South Africa.^{54 55 56}

Morrell et al⁶⁰ argued that, in the HIV era, there are many compelling reasons why fathers should be more available and participant. As a result of these factors, when children lose their mothers, childrearing responsibilities often fall on elderly grandmothers and other female relatives.⁶¹ Elderly grandparents in other parts of Africa are faced with similar challenges and responsibilities.⁶²

2.3 Palliative care needs of African palliative patients

Literature was reviewed in terms of how research addressed or identified needs and outcomes, and how patient context was relevant to lived experience of life-threatening illness for African palliative care patients. Murray et al's⁶³ study contrasted needs in the developed (Scotland) and developing (Kenya) world for a group of dying cancer patients. They used qualitative research methodology and interviews conducted in mother tongue for each group of participants. The thematic analysis was sensitive to the cultural dynamics that could influence interpretation. Their study showed that the experience of dying of cancer was different for the each group. In the Scottish cohort spiritual needs and the concerns regarding the prospect of death were most evident and this contrasted with the Kenyan cohort where pain and symptom related needs dominated. The Scottish cohort had access to medical and specialized palliative care that was, for most Kenyan patients, unavailable. Palliative care needs were present in both groups, but patient needs appeared to be influenced by context. Significantly the study commented that lack of resources resulted in more unmet physical needs in terms of symptom burden in the Kenyan group. Lived experience of disease was also influenced by the cultural and local context. Few Kenyan patients had access to opioids, there were few medical, financial and municipal resources and cultural issues influenced care giving and home nursing. The Scottish group struggled with the prospect of imminent death and struggled to share this with family and friends. The burden of potentially curative treatment regimes was high and care-giving responsibilities for family members were significant.

While the relevance of Murray et al's⁶³ study to this work may be limited, in that it did not address the issues facing HIV patients, it makes important observations regarding the influence of context. Kikule⁶⁴, who described the experience of people dying of HIV and cancer in Uganda, developed a questionnaire to collect quantitative data. This questionnaire was not based on a previously validated palliative care needs assessment tools but the sample size was 173 and her findings for cancer patients paralleled those of a similar qualitative study, thus suggesting validity and reliability. This questionnaire was adapted by Uwimana and Struthers⁶⁵ in their mixed quantitative/qualitative study of the palliative care needs of people living with HIV in Rwanda which sampled patients and healthcare workers involved in HIV care. These two studies demonstrated a similar hierarchy needs: pain and symptoms control and analgesia access, the need for financial assistance, psychological support and home based care. Pain and symptom control was most important for Kikule's cohort, and economic needs for Uwimana and Struthers' cohort. Kikule⁶⁴ further showed similarities in the needs of her population irrespective of their primary diagnosis (cancer or HIV), and these mirrored the needs of cancer patients in Murray et al's Kenyan cohort⁶³.

Uwimana and Struthers⁶⁵ noted that needs of patients in rural areas may not necessarily be the same as those of urban patients. This limitation is relevant as it motivates for community specific research but also demonstrates the tension between such results which, while they will inform local service provision, may not be transferable. These studies demonstrate the value of mixed quantitative and qualitative research methodology to describe palliative care needs and that this approach can be used successfully in research populations where cultural and language diversity occurs both in participants and researchers. This methodology is contrasted with a prospective census that collected quantitative data conducted by Collins and Harding³⁸ in Tanzania. Presenting palliative care needs were collected using a piloted data sheet and statistically analysed. It is relevant to note that while physical symptoms and the need for psychosocial support were identified, fewer conclusions could be drawn regarding the influence of context and culture as results were quantitative and statistical.

Palliative care needs from five African countries were surveyed by Sepulveda et al⁶⁶ using a data collection tool adapted from Kikule's questionnaire, to identify palliative care needs at the end of life. This study focused on end-of-life issues for cancer and HIV patients, and again physical symptoms, accessible affordable analgesics, financial issues and psychosocial pressures were identified. The pressure on families who accept the burden of care was demonstrated and authors noted that care had to be provided within the constraints of a family or community. It also demonstrated that there were similarities in experienced needs in different African countries.

These studies talked to palliative care needs of HIV and cancer patients in specific African communities, and while they commented on the influence on needs of context, they did not directly address the outcomes of palliative interventions within the community and cultural context of patients who were able to access palliative care as an available local resource.

Thus, it appears that palliative needs occur for all patients facing life-threatening illness,^{6 28 34 63 64 65 67 72 73} but how these needs are experienced, ranked and addressed, and possible outcomes of care may be culture and context specific.^{16 63 64 65}
⁶⁶ Assessment tools used in the palliative care context should also be appropriate. Powell et al⁴⁰ questioned the use of outcome measurement tools in Africa that have only been validated in resource rich countries. The APCA African Palliative Outcome Scale has now been developed and validated in Africa to provide a relevant assessment tool.¹⁹ The important of context was noted^{63 64 65 66}, but what is required to deliver care that sensitive to these differences is less clear. It does appear, however, that culturally diverse teams are better able to meet the needs of a culturally diverse population.⁶⁷

2.4 Palliative care for HIV in the ARV era

The implementation of palliative care requires that a service or approach is available to evaluate and meet patient and family needs and that the outcomes of met needs can be

measured. Higginson⁶ reviewed the development of hospice and palliative care services in the developed world and evaluated models and places of care, the tension between curative, palliative and end of life care, and how outcomes can be best measured.⁶ Even in the developed world, barriers to care have been shown to inhibit the application of palliative care for HIV positive patients⁶⁸ and patients themselves may have lower expectations if they are from lower socio-economic environments⁶. We are reminded that measuring needs and measuring patient outcomes is complex in palliative care.⁶

The needs of palliative care patients are considered within the framework identified in the WHO definition of palliative care and encompass the domains: physical, emotional, social and family, spiritual. In Africa these needs may also include the special needs of women, financial and food related concerns, housing, cultural considerations.^{2 16 17 64} Meeting the needs of patients and family members is described as total care.¹⁷

It is recognised that palliative care is an important aspect of HIV care⁶⁸ and improves patient outcomes across a spectrum of problems experienced throughout the whole trajectory of HIV infection⁶⁹. Selwyn et al reported on palliative care provision in a teaching hospital in the USA and showed that patients require both HIV management and palliative care.⁶⁷ One model of care is to integrate counseling, testing, treatment for OI's and palliative care which contributes to curative and preventative care, and community based home care programmes can interface with established health care services and the people they serve.⁷⁰ This is an approach used by hospices in South Africa to provide care to people living with HIV/AIDS has now expanded to include treatment support for ARVs.⁷¹

ARV access has challenged the need for ongoing palliative care to HIV positive patients, but it is clear that palliative care continues to be relevant and necessary despite the availability of ARVs.^{67 68 69 72} Brechtel et al⁷³ reported on outcomes for patients at a New York teaching hospital on HAART using validated assessment and

outcome scales. They note that while benefits were measured in terms of improved CD4 count, weight and reduction in viral load, positive outcomes in the areas of pain, symptoms and physiological well being were less clear, suggesting that needs were ongoing despite HAART. Harding et al⁶⁸ identified a range of ongoing issues for patients on HAART in the developed world in their review paper that considered access and equity in HIV/AIDS palliative care. These include higher death rates, side-effects and toxicity, HIV related malignancies despite HAART, late presentation and the development of new HIV associated co-morbidities. Concerns of new emergent co-morbidities in the developed world are noted by other authors.⁷⁴ These developed world studies identified that challenges for HIV positive patients were ongoing and that access to HAART did not mean that palliation and end of life care was no longer required.^{69 67 72} Clear demonstration of these trends for South Africa and Africa remains to be documented but it seems unlikely that wide access to ARVs in South Africa will mean that palliative care is no longer required.

2.5 The economic implications for individuals and families living with HIV infection

The HIV epidemic in South Africa has affected mainly the poorest and most marginalised groups.⁷⁵ In the Eastern Cape almost three quarters of all children live below the ultra poverty line²⁹ suggesting that the province is particularly vulnerable. In contrast to many other life-threatening diseases, the natural course of HIV can be protracted and this places households under financial pressure over a long period of time.⁷⁶ This occurs both while the young members of the family are ill and not able to contribute to household and family income, and after death when the loss of income and the care burden of orphaned children remain.^{61 62}

Good health is an important resource for those seeking to escape poverty and the most common causes of household poverty are injury, illness and death.⁷⁷ Those who are poor are also less able to access health care. Poor families have been shown to spend

a greater proportion of household income on health care than better off families.⁷⁸ Bachmann and Booysen⁷⁹ examined the effects of HIV at household level in a South African context. Their controlled cohort study was conducted over a period of time to limit the influence of population wide changes that could occur in times of rapid political, demographic and economic change and with a study design that addressed limitations they had identified in other studies. Both urban and rural, HIV affected and unaffected populations were examined and it was identified that HIV affected households in both urban and rural areas were, on average, larger, poorer and had lower levels of employment. It was also identified that illness at baseline was independently associated with lower income and expenditure at baseline. Bachmann and Booysen⁷⁹ note that this is consistent with other studies from Africa and Asia and Kikule⁶⁴ and Uwimana and Struthers⁶⁵ noted the economic pressure experienced in HIV affected households in Kenya and Rwanda. The added pressure of HIV burden at household level is not necessarily alleviated by access to free-at-point-of-service ARV programme as infected and affected households incur other costs to access treatment.³⁶ Thus the poor are more likely to be infected and the infected become poor^{77 79} but Bachmann and Booysen⁷⁹ note that elucidating the mechanisms that drive this are difficult to quantify. There also appears to be a relationship between income from employment and income from social welfare that is influenced by HIV infection as illness in households increased welfare income to alleviate poverty while it was accessed, but decreased employment income.⁸⁰ Tladi⁸¹ makes an important observation that even with similar levels of education, poor women were less likely to have effective means with which to protect themselves from HIV infection, suggesting that poverty places an individual at more risk, and that education is less protective. Bachman and Booysen⁸⁰ demonstrate the importance of complementary policies, to provide disease modifying interventions in the form of ARVS and income support, in the fight against HIV/AIDS in South Africa. Thus the literature demonstrated the complex relationship between HIV infection and poverty and illustrated that the poor are at risk of HIV infection and the infected become poor.

2.6 Palliative care for HIV positive patients in Grahamstown

For this research to be relevant consideration was given to identifying existing literature that referred specifically to the Grahamstown HIV positive palliative care population. A Google scholar search using keywords (Grahamstown, HIV, palliative) yielded 10 hits and four relevant papers were reviewed. Kelly and Ntlabati³² considered the impact of marketisation of municipal services on treatment support and care of HIV positive patients in the town. The survey collected quantitative data to describe demographics and qualitative data to describe lived experience. This data not only commented on the socio-economic realities of HIV positive patients living in Grahamstown but could be used as a validation tool for this researcher's demographic data collected in similar domains. Kelly and Mzizi³⁵ reported on the implications for local AIDS care and support programmes shortly after ARV rollout commenced in 2005. They identified important areas where the rollout programme would place extra demand on both the local hospice and the health care infrastructure in order for HIV care to be sustainable in the town.

Jameson described palliative care needs of stage III and IV HIV patients who were medical ward inpatients in Settlers Hospital in 2005.⁸² She identified needs across the palliative care domains but poor symptom control dominated. This was the only study identified that considered palliative care needs for Grahamstown HIV positive patients. The mixed quantitative qualitative data was not collected using previously validated assessment tools but was able to inform the development of a dedicated inpatient palliative care facility to ensure that good palliative care principles were the foundation of the care provided. This was followed by another study by the same author who reported on outcomes for patients who had access to inpatient palliative care.³⁴ Despite the small sample and the lack of a control group, this study suggested that outcomes were improved for the very sick who accessed inpatient palliative care. Jameson³⁴ also identified that a range of health care facilities were referring to the inpatient unit and this suggested integration of the service into the wider health care infrastructure of the town.

2.7 Motivation for this research project and selected research methodology

Clearly there are very little published data describing palliative care access by HIV positive patients in Grahamstown. No studies explore the relationship between patients and hospice as a palliative care provider to consider patient needs within a specific context and community resource that review outcomes of palliative intervention. The need for relevant specific research has been identified and described as a priority in literature reviewed. A mixed quantitative qualitative research methodology demonstrated valid and reliable results to describe demographic data and palliative care needs.^{63 64 65} This research project was developed to consider the context and palliative care needs of HIV infected patients and utilized a mixed quantitative qualitative research methodology which was based on previously validated data collection tools. Thus the literature review supported both the theoretical notion that this research is important and supported research methodology selected. The key issues identified in the literature review that motivated the research question were firstly, the importance of individual, family, economic and cultural context as these demonstrated the provision of culturally sensitive, patient centered care. Secondly, the relevance of palliative care to address the pain and suffering experienced by HIV positive patients, even in the ARV era.

CHAPTER THREE

3. AIMS AND OBJECTIVES

AIM: To identify individual context and met and unmet palliative care needs of stage III and IV HIV/AIDS isiXhosa speaking patients in the Grahamstown Hospice service

Objectives:

1. To identify the social, educational, economic, geographic, medical, cultural and spiritual context of the research population
2. To identify patient needs in the five domains of palliative care
 - a. Physical
 - b. Emotional
 - c. Social / family
 - d. Spiritual
 - e. Economic
3. To establish whether patients perceive their needs in each domain to have been met
4. To establish whether patients feel they had been involved in medical decisions regarding their care

CHAPTER FOUR

4. METHODOLOGY

4.1 Introduction

This is a descriptive analytic study. A mixed quantitative qualitative research methodology was selected as it is essentially multi-method in focus and allowed for a line of questioning that enabled connections and associations to be drawn between patients' lived experience, larger social and cultural environments and the challenges of living with HIV infection in Grahamstown.⁸³

These difference data collection methods explore how people experience life events and the meaning given to those events.^{84 85} Qualitative research design was selected as it was an approach that allowed for data collection to describe phenomena within a specific setting and to develop insights to the social, cultural and health reality of the respondents in the study.⁸⁶ Different data collection tools were developed to triangulate data, thus combining quantitative and qualitative data to complement each other.^{87 88} The research question informed research methodology selected.

4.2 Participant sample

The population sampled for data collection was stage III and IV HIV/AIDS patients using the Grahamstown Hospice service. GH patients are visited at home according to their category of care (appendix 1) by a professional member of hospice staff or a care worker. Hospice care workers caring for isiXhosa speakers are generally isiXhosa speaking members of the same community. Home visits provide an array of services from medical to social to providing food parcels and helping with transport to medical appointments. Patients who are in hospital are also followed up by GH during admission and discharge.

Adult patients registered with the GH during the study period September 2006 to May 2007 were eligible as participants in this study. This included eligible patients already registered on 1 September 2006 and any new admissions fulfilling the inclusion criteria during the study period.

Selection criteria used to include participants were:

1. Adult isiXhosa first language speakers (over 18 years of age)
2. HIV positive patients with stage III or IV disease at time of admission at GH
3. Patients living in the Grahamstown municipal area
4. Current hospice patients, both home-care and in-patients

The criteria used to exclude participants were:

1. Patients too ill to participate
2. Patients with HIV dementia or confusion
3. Children (under the age of 18 years)

The hospice social worker reviewed the list of all patients who met the inclusion criteria, those who were eligible were approached and patients who consented were included in the study. The enrolment process continued until May 15, 2007 and the interviews were concluded by the end of May 2007. The aim was to enroll 40 patients in the study over a six month period, or until there was saturation of data. All eligible patients were approached by either the social worker or one of two registered nurses, but not by the nursing sister involved in their care in order to minimize the possibility of patients feeling obliged to participate. Patients were handed a patient information sheet (appendix 2) and invited to participate in the study and informed written consent (appendix 3) was taken by an isiXhosa mother tongue speaker.

4.3 Data collection tools

Data was collected using three collection tools: demographic data collection sheet to collect demographic details directly from patient records, a structured questionnaire and a semi-structured interview. These are each described below in more detail.

Questionnaire and interview design were informed by the aims and objectives of the study. The data collection tools were required to: firstly, extract demographic data placing respondents within a particular context that was postulated to inform and influence their palliative care need, secondly, describe palliative care needs as defined by the WHO definition of palliative care, thirdly express elements of the relationship between the patient and GH as a health care provider that contributed to the therapeutic relationship, and the meeting of palliative care needs, fourthly, reflect outcomes that the patient perceived to be beneficial, and finally, describe how involved patients had felt in decision making.

4.3.1 Demographic data from patient records

Demographic data was collected from the GH patient files of all enrolled participants. Included details were to establish context (social, education, economic, residential) and place the patients within a cohort of isiXhosa mother tongue speakers, living in Grahamstown, with stage III or IV HIV/AIDS. Demographic data was extracted from existing patient records at GH and entered into the demographic data sheet (appendix 4). The only information not on the GH admission form related to highest level of education.

4.3.2 Structured questionnaire and semi-structured interview design

The structured questionnaire (SQ) and semi-structured interview (SSI) were designed in conjunction with one another. The structured questionnaire (appendix 5) focused on the following elements

- The relationship between Hospice and the patient, and reason for referral
- Palliative care needs and patient ranking of needs
- Patient participation in decision making

The foundation for the assessment of palliative care needs, involvement in decision making and self ranking of needs was based on the Palliative Outcomes Scale (POS)⁸⁹ developed by Hearn and Higginson⁹⁰ at Kings College London (appendix 6). This is a validated outcome tool and is used internationally and has been validated in the African setting.⁹¹ The researcher is a registered POS user.

SQ questions v, vi, viii, xiii were directly from POS. SQ questions xi and xii modified question 10 in POS. SQ question xiv modified POS question 5 which relates to information and communication. POS question 6 and 8 were omitted from the SQ as these elements were expanded in the semi-structured interview. Question 9 was excluded as it was not directly relevant to the aims and objectives of the study.

The questions in the SQ on spiritual issues are based on the Spiritual Assessment Tool FICA (appendix 7) developed by Puchalski and Larson⁹² and Puchalski and Romer⁹³ at George Washington University. The first two elements of FICA were used in the SQ: do you have a faith and how important is it in your life? The questions regarding religious or spiritual community were incorporated into the SSI. It was acknowledged at the outset of questionnaire design that eliciting data regarding the spiritual lives, faith and beliefs of the amaXhosa participants would be challenging.

Questions that were not from POS and FICA were added to elicit a demographic detail not available from patients' Hospice folders (SQ question ii, iv), to describe how patients positioned Hospice (SQ question i) or to identify what patients' understanding was for their referral to hospice (SQ question iii). SQ questions i and iii were expanded in the SSI but were not adapted from another previously validated tool. SQ question iv was

included in line with the aims and objectives of the study and contributed to the establishment of spiritual and cultural context.

The semi-structured interview schedule (appendix 8) was designed to elicit phenomenological data to reflect lived experience. The semi-structured interview (SSI) was designed with open ended questions. These questions expanded on the questions asked in the structured questionnaire to allow patients to use their own words to express themselves.

SSI questions 1 to 6 expanded SQ questions i and iii. SSI questions 7 to 22 expanded on the palliative care need domains issues identified in the SQ, identified the resources patients mobilised and explored how various people and agencies were able to meet needs and asked patients what needs they still had. SSI question 23 and 24 expanded on POS question 5 to establish how informed and involved patients felt in decision-making.

4.3.3 Development of the SQ and SSI

Once the framework for the three data collection tools was identified, and POS and FICA selected, the process of developing the tools progressed with discussion and consultation between the researcher, the research supervisor and GH staff members. GH staff members involved included professional nurses, the GH social worker, the research assistant and GH psychologist.

The standard GH admission form, POS and FICA were scrutinized to align questions with the aim and objectives of the research. IsiXhosa speakers at GH contributed significantly in the consultation period to developing data collection tools that would both identify the right questions to ask and the right way to ask them. The researcher gave consideration to the particular challenges of spiritual needs and consulted with an isiXhosa speaking theologian at Rhodes University. Assistance was sought from

academics in Grahamstown who had done research in the HIV field to consider the elements of context that could potentially influence needs.

Several drafts of the SQ and SSI data collection tools were reviewed by the researcher, supervisor and GH staff. The GH social worker, and two GH sisters, all isiXhosa speakers made significant input. In the course of developing the tools certain of the POS and FICA questions were amended or omitted as previously described. The questions regarding the patients' relationship with Hospice were developed alongside both POS and FICA to consider how understanding of illness, palliative care and GH as an organization influenced palliative care needs and outcomes.

4.4 Validation

4.4.1 Validity and reliability

The framework for the structured questionnaire and semi-structured interview were POS and FICA. These are assessment tools that are used in palliative care and have been previously validated. For research to be valid it has to measure what it says it is measuring, in this case palliative care needs. Consideration was given to how well the three data collection tools and the data collection method measured patients' context and needs. Research that is reliable comments on how accurately data is produced i.e. that the same conclusions can be drawn from data collected using different methods and data collection tools, from data collected by different people and from data collected at different times.^{86 94} Validity and reliability are enhanced by using standard data collection tools like POS and the Spiritual Assessment Tool and by using different data collection tools that are collecting the same information, whose results can be cross-checked against each other. Validity and reliability ensure that data collection tools are asking the correct questions, the data collection tools will elicit similar data if used at another site in another population and that similar conclusion can be drawn from different data sets.

Validity and reliability was considered at three stages during the research

1. Identification of the foundation needs assessment tools
2. Development of the research tools
3. Evaluation of the completed pilot study as described below

As the questionnaire development was based on POS and the Spiritual Assessment Tool, the validation process described for the development of POS was taken into account when evaluating reliability and validity of these data collection tools.⁹⁰ It must be noted that the original POS was designed with two parts, one that the patient completes and a second that the PC staff complete. This research project focused only on the patient and only used the patient questionnaire.

The following aspects of validity and reliability were considered: context validity, face validity, construct validity, internal consistency and test/re-test reliability, equivalence and inter and intra-judge reliability.^{85 86}

4.4.1.1 Content validity

The initial literature review and selection of POS and FICA contributed to ensuring that data would cover important PC need domains and yield relevant data. All three data collection tools contributed to relevant information that informed, contextualized and detailed patients palliative care needs. The data collection tools identified patient needs in all domains described in the WHO definition of palliative care and explored patient and local context as required by the aims and objectives.

4.4.1.2 Face validity

The researcher subjectively considered the relevance and presentation of the questionnaires. It was felt that the questions were asked in a clear, unambiguous way and elicited the information required by the aims and objectives of the study.

4.4.1.3 Construct validity

Construct validity ensures that the data collection tools measure what they say they are measuring. Both the questionnaires were based on previously validated widely used needs assessment tools. The constraints of this research project did not allow for POS or FICA to be administered alongside the SQ and SSI.

4.4.1.4 Internal consistency and test/re-test reliability

The data collection tools were only administered once so no comment could be made on internal consistency or test/re-test reliability. Statistical analysis was not carried out to compare data from each data collection tool as data collected was largely qualitative.

4.4.1.5 Equivalence

Data was collected by three different data collection tools which increased reliability, however, no data was collected using existing tools (POS or FICA) for comparison.

4.4.1.6 Inter and intra-judge reliability

Data was collected by one individual and on one occasion, thus no conclusion could be drawn regarding inter- and intra-judge reliability.

4.4.2 Triangulation

Triangulation has been used in this study design to assess the validity and reliability of the data collected. Triangulation sources and data collection methods have been selected to complement each other, ensuring that the data collected has “different biases, (and) different strengths”.⁹⁵ Two different sources were selected, firstly patient records to elicit demographic data and secondly, a structured questionnaire that elicited yes/no, or answers to closed questions and a semi-structured interview that elicited answers to open-ended questions, collecting data directly from the respondent. Different data collection methods were also used, which resulted in different types of data: quantitative information – demographic data, Likert scale data – quantitative

display of qualitative data and qualitative data – interviews (qualitative text). These different data sources, and data collection methods were selected so that each data set could be compared against each other, to complement and strengthen data collected with each data collection tool and improve reliability.⁹⁷

4.4.3 Pilot study

A three patient pilot study was conducted to test the three data collection tools and to consider how accurately each data set was collecting data which allowed assessment on reliability.

The first three patients enrolled who met the selection criteria completed the structured questionnaire and one of these completed the semi-structured interview with the intent of piloting the data collection tools and thus test the research design and to identify possible problems with the questionnaires.⁹⁷ The SQ and SSI were conducted in exactly the same way as the subsequent data collection. The three completed SQs and one SSI from the pilot study were reviewed to consider how successful and efficient the data collection tools were in eliciting data, to consider how questions had been interpreted and if the responses to both questionnaires elicited data that related to the aims and objectives of the study. The researcher and research assistant discussed the interpretation and responses to the questions and both SQ and SSI were reviewed. Completed questionnaires were reviewed to assess how well data from each data set related to the self ranking in the SQ and how data from the SQ related to the SSI. The issues that were identified in the self ranking were covered in both the SQ and SSI. The pilot process resulted in valid documents which were then used for the data collection.

4.5 Translations

4.5.1 Structured questionnaire form and semi-structured interview schedule translation

The structured questionnaire form and semi-structured interview schedule were developed and translated in consultation with the supervisor and GH staff, including isiXhosa mother tongue registered nurses, the social worker and the care worker, to ensure that content and meaning of the questions would be clear. The purpose of the study was discussed with the GH social worker, registered nurses and the research assistant. It was important that the conceptual framework for the questions was understood by the isiXhosa speakers who were involved in translations. The initial development was completed in English. At this stage the English wording of the questions was already giving thought to how easily they would translate.

The structured questionnaire and semi-structured interview schedule were translated from English to isiXhosa by an isiXhosa mother tongue speaker who was a non-medical person not involved at GH at all. This was to ensure that language used in the questionnaire would be more likely to be 'non-medical'. Both questionnaires were back translated and reviewed by two isiXhosa GH staff members (social worker and care worker) in consultation with the researcher and discrepancies were discussed. Attention was paid to both how the questions were phrased and the difficulties with translating certain concepts from English into isiXhosa. This ensured that the nuances of the word usage were true to the original question. The final translated questionnaire was reviewed again by a mother tongue English speaker who is fluent in isiXhosa.

4.5.2 Transcription and translation of completed semi-structured interviews

SSIs were recorded on audiocassettes. Each tape recorded completed semi-structured interview was transcribed and translated by an isiXhosa mother tongue speaker who is fluent in English. She listened to each recording a number of times to get a sense of

the whole and then transcribed each verbatim in isiXhosa. Inaudible speech was noted as [inaudible] in the transcription. The isiXhosa transcription was then translated verbatim into English. The English transcriptions were reviewed by an English mother tongue speaker fluent in isiXhosa who compared the English transcription with the original interview recording to ensure integrity of translation. Only isolated minor discrepancies were noted and these were discussed by the translators.

4.6 Training of involved hospice staff and research assistant

The researcher had training sessions with the GH social worker and registered nurses who recruited patients before they approached any patients for enrolment in the study. This training covered the purpose of the study and ethical issues including: patient confidentiality, protection from harm – disclosure and not to coerce patients to participate or consent. It was stressed that all patients had to be informed that their participation was voluntary and that their refusal to participate would not compromise the care that they received from GH in any way.

The researcher had training sessions with the research assistant who translated in the interviews (GH care worker) prior to enrolment of patients and prior to the interview process beginning. The first session covered issues discussed above pertaining to purpose of the study and ethical issues. The second session covered aspects of the interview process and how to administer questionnaires in a consistent way. The research assistant is bilingual in isiXhosa and English.

4.7 Data collection

The social worker handed the completed consent forms to the researcher and all patients enrolled were placed onto a coded list to protect confidentiality. The original patient list with interview codes was kept separately and SQ were identified by a written code on each questionnaire and each SSI was identified by a spoken code at the

beginning of each recording. Demographic data was collected from the patient's hospice files prior to the interviews being conducted. If there were missing data, this was noted for clarification at the time of the interview, and the patient was asked to provide the information verbally.

Once patients had agreed to participate, had given written consent and demographic data had been collected, interviews were scheduled and completed. One patient withdrew before the interview could be completed. All enrolled patients completed the SQ and every third patient was numerically selected to complete the SSI.

The interview period ran from January to May 2007. At this point saturation of information was reached and the answers were becoming repetitive.

The researcher and the research assistant (the same person for the duration of the study) were present at all interviews. Face to face interviews were conducted with each enrolled patient and privacy ensured. A standard introduction and information process was followed at the start of each interview. If there were missing data from demographic data collection (patient file information) that information was sought prior to starting the structured interview. Structured questionnaires took between 10 and 15 minutes to complete and semi-structured interviews took between 20 and 30 minutes. Twenty-six patients completed the SQ and 7 completed the SSI. At the end of the interview patients were thanked for their participation.

All structured questionnaires were administered in isiXhosa. The questions were read verbatim to each patient as per the questionnaire. Patients were invited to have the questions re-read to them as many times as was necessary. Questionnaires were read to each patient to ensure that the patient's level of literacy did not influence the accuracy of interpretation of the questions. Answers were documented by the research assistant and the researcher and collated after the interview was completed.

All SSI were conducted in isiXhosa. Patients were informed that the interview was to be taped and that their name would not be used in the recording. A standard introduction process was followed. A test run recording was completed to ensure that the quality of the recording was adequate and to put the patient at ease, familiarizing her or him with the recorder. At the end of the interview patients were thanked for their participation.

4.8 Ethical considerations

4.8.1 South African good research practice

Good research practice considers those elements that contribute to research that is both ethically and scientifically sound. The South African Department of Health (DOH) has published guidelines for good practice in the conduct of clinical trials in human participants.⁹⁶ There are no formal DOH guidelines for good practice in South Africa for medical research conducted on human subjects who are not part of clinical trials, however researchers are bound by the professional conduct rules of their professions, accepted ethical standards and the ethics committees that review research proposals⁹⁷. Despite the fact that this research was not a clinical trial the ethical principles described in the DOH guidelines are universal and supported by the Helsinki Declaration⁹⁸ which refers to any medical research involving human subjects. Researchers have a responsibility to those who participate in their research and to the scientific community to produce honest and accurate research. Both the DOH guidelines and the Helsinki Declaration make special mention of the responsibilities of a researcher who is conducting research in a vulnerable population. The design and conduct of this study was executed within these principles and guidelines.

4.8.2 Ethical considerations

Research in the palliative care population has particular ethical challenges. Patients are often very ill and this may make participation in an interview based research project

difficult. Patients who are well enough at the time of enrolment may be too ill to participate when the interview takes place. Patients should also be comfortable to withdraw at any point and be reassured that this will not compromise their quality of care in any way. This interview population was particularly vulnerable. A number of them were ill and two were in the in-patient unit at the time of the interview. In addition, the research was conducted in a population of low socio-economic means who had limited experience or understanding of a research process. It was imperative that patients did not feel coerced to participate. Informed written consent was taken from each patient in isiXhosa and verbal and written information was presented in isiXhosa. Palliative carers engage in difficult conversations and they are trained to enable them to support patients in sensitive issues. The research protocol also included a distress protocol. Data collected from this vulnerable population will reflect on palliative needs that have not previously been researched and will allow comment on the quality of the palliative services they have access too, and this will add to the value of the research.

4.8.3 Distress protocol

If the patients appeared distressed or reported that they felt distressed the interviews were interrupted and the distress protocol followed (appendix 9). Patients were asked: "Would you like to stop the interview now?" If they said they would like to stop, the interview was immediately abandoned. Immediate plans were made for them to see the GH social worker and their GH sister as soon as possible. Patients were counseled and only escorted back to the waiting area once they no longer demonstrated their initial signs of distress and said that they no longer felt distressed. The researcher followed up with the GH social worker and nurse personally to ensure that agreed meetings to support the distressed patient took place. One patient required this intervention.

4.8.4 Considerations for Grahamstown Hospice patients

All patients were followed up by their regular GH sister following the interviews. The researcher kept contact with the GH social worker and the clinical head of GH throughout the interview period.

4.8.5 Record management and confidentiality undertakings

All information collected was confidential and was only reviewed by the primary researcher. Participants were anonymised and no identifying patient detail appeared on any completed questionnaires or semi-structured interviews. Patients were only identified to refer any needs back to the GH for intervention and this was discussed with the patients at the time of the interview and their wishes documented. Consent was taken for this information to be given to GH by the researcher.

All persons – GH social worker, GH sisters, research assistant and translators – involved in the study completed confidentiality undertakings. Patient confidentiality was explained and the importance of confidentiality and privacy stressed.

4.8.6 Ethics and scientific approval

Ethics and scientific approval was granted by the University of Cape Town (appendix 7). This study was discussed with the staff of GH and Settlers Hospital. Permission was granted by Grahamstown Hospice (appendix 8), Settlers Hospital (appendix 9) and Settlers Hospital ARV rollout programme (appendix 10) to conduct this study, interview GH patients who were in PCU, and to access ARV rollout data.

CHAPTER FOUR

4.9 DATA ANALYSIS

All data collection tools that collected data from the same respondent were assigned the same alphanumeric sequence name. The alphanumeric code distinguished between male and female respondents. Data from all three data collection tools were analysed as a whole, but where relevant, distinction was made between female and male respondents.

4.9.1 Demographic data

All the demographic data were entered onto an Excel spreadsheet and descriptive statistics of mean, median and standard deviation were calculated where appropriate. Standard deviations were calculated for certain key categories in order to establish if there were statistical differences in relevant figures for females and males to align results with national trends.

4.9.2 Structured Questionnaire

Likert scale data from the SQ resulted in scores from 0 to 4. The recorded frequency for each Likert scale answer was added and totals for each numeric category were calculated as a percentage. This process enabled semi-qualitative data to be analysed quantitatively. Yes/no answers were totaled and percentages calculated.

The qualitative data from the list “What are the three biggest problems or worries you have today?” from the structured questionnaire were analysed through thematic analysis. The list was reviewed and then grouped into problems or worries that related to physical, social or family, economic, emotional and spiritual themes in line with the domains of palliative care needs as described in the WHO definition of palliative care.

Similar answers were placed together under these five domains. All answers in similar answers within each theme were divided into categories. Themes were ordered from the theme with the most number of similar responses to the theme with the least number of similar responses. Categories within each theme were ranked in order from the category with the greatest number of similar responses to the category with the least number of similar responses. This identified the patients' ranking of their problems or worries from most prevalent to the least prevalent. The themes and categories identified were analysed alongside the needs identified in the thematic analysis of the SSI.

4.9.3 Semi-structured interview

All the interviews were read and re-read by the researcher (immersion in the data) until familiarity was attained.

Data was sorted in the following sequential manner

1. Each answer was examined in itself as relating to the particular question.
2. All answers relating to the same question were examined in relation to each other
3. Answers relating to the same or similar topics (e.g. physical symptoms) from each respondent from the SSI were related to answers from the same respondents from the SQ pertaining to these topics. Thus topics from the structured questionnaire were expanded and strengthened by answers from the same respondent in the semi-structured questionnaire.
4. All needs or issues identified in each interview were listed. These were grouped into categories, sub-themes and themes.

Steps 1 through 4 continued the process of familiarization. The data was not analyzed interpretively or reflexively at this point during the process, but answers were examined in themselves. The literal interpretation of the data was considered to examine how

answers were phrased and words used.⁹⁹ Once the thorough process of familiarization was complete and answers from the structured questionnaire were compared to the semi-structured questionnaire, all seven SSQ interviews were analysed using a coding system

4.9.4 Coding system

The coding system was informed by the aims and objectives. It resulted in the development of the categories, sub-themes and themes. The researcher acknowledges that identifying categories is influenced by the researcher and is not neutral, and that choosing a particular system makes suppositions about what is found or not found, and will determine how data can be assessed later.⁹⁹ The cross sectional categorization model allowed all data from the SI to be consistently analysed.⁹⁹

Interviews were interpreted interpretively to consider what data was thought to mean and reflexively to consider what could be inferred from them. The researcher acknowledges her role in the process. Reflexivity locates the researcher in the process of generation of data and perspective given to the data. Context was noted in relation to the interpretive and reflexive analysis of data. The framework used for coding was then applied to each interview (step 6)

Each category was allocated a colour code. All the interviews were re-read and issues that corresponded to different categories were colour coded, cut out and glued to index cards. The interview code and page number was written on each index card. All similar issues were then grouped together and categories were further refined. During the refining of the themes, sub-themes and categories, mind maps were drawn to represent the thinking as the analysis progressed.

CHAPTER FIVE

5. Results

5.1 Demographic data

In total 26 patients were enrolled in this study of which 19 were female and 7 male (Table 1). Ages ranged from 23 to 56, with most females falling into the 30-39 age cohort, and the males being more evenly distributed across the age cohorts. Mean age for females was 36.5 and males 41.4. The mean ages were similar for females and males ($p=0.2039$).

Table 1: Age distribution of the 26 respondents in the study

Female	No of pts	% of total female	Male	No of pts	% of total male	All pts	%
20-29	3	15.8	20-29	1	14.3	4	15.4
30-39	12	63.2	30-39	2	28.6	14	53.8
40-49	3	15.8	40-49	2	28.6	5	19.2
>50	1	5.3	>50	2	28.6	3	11.5
Total	19	100	Total	7	100	26	100
Mean	36.5		Mean	41.3		Mean	37.8
SD	7.9		SD	9.1		SD	8.4

The majority of the sample was un-married (88.5%), and this percentage was similarly reflected in the gender breakdown (Table 2).

Table 2: Marital status of the 26 respondents in the study

Female	No of pts	% of total female	Male	No of pts	% of total male	Total number of married pts	% of total pts
Married	2	10.5	Married	1	14.3	3	11.5
Unmarried	17	89.5	Unmarried	6	85.7	23	88.5

There was a notable contrast in number of dependents for female and male respondents. The majority of males had no dependents and more than three quarters of the female patients had dependents (Table 3).

Table 3: Dependent numbers of the 26 respondents in the study

Dependents	Female	%	Male	%	Total	%
0	3	15.3	5	71.4	8	30.8
1-2	13	68.4	2	28.6	15	57.7
3+	3	15.8	0	0	3	11.5
Total	19	100	7	100	26	100

All patients had attended school, but none had tertiary education. The majority of the sample had secondary level education with the mean for the whole sample of Grade 9.

Eighty-eight percent of patients lived in households with 3-10 members, with a mean of 5.5 householders across the sample (Table 4). Male patients lived in larger households than female patients

Table 4: Household numbers for the 26 respondents in the study

	1-2	3-6	7-10	>10	Total	Mean	Median
Female	2	12	5	0	19	5	5
Male	0	4	2	1	7	7	6
Total	2	16	7	1	26	5.5	5.5

None of the patients in the sample were employed. Thirty-eight percent of patients in the sample had no personal income and 61.5% had disability grants (Table 5). Four female patients were supporting all of their household members with their grant. Sixty-five percent of patients had income contributed by other householders and some households had multiple income sources.

Table 5: details of household income sources of respondents of the study

	Patient has no income	Patients with disability grant	No income contributed by other householders	Income from other householders	Households dependent on income from outside the house	Households dependent on patient's disability grant
female	7	12	4	12	2	5
male	3	4	0	7	0	0
% female	36.8	63.2	21.1	63.2	10.5	26.3
% male	42.9	57.1	0	100	0	0

According to the WHO clinical staging of HIV/AIDS¹⁰⁰, seven respondents were stage III at admission and 19 were stage IV. Seventy-nine percent of the female respondents and 57% of the male respondents were stage IV at admission. Admission CD4 counts ranged from 1 to 366, with 36.6% below 50 and 31.8% between 50-100 for the whole sample (Table 6). There was no significant difference in admission CD4 counts at admission for female and male patients ($p=0.5553$). Admission CD4 counts were not available for three female and one male respondent.

Table 6: details of admission DC4 counts for respondents in this study

	CD4 <50	CD4 51-100	CD4 101-200	CD4 >200	Total	Median CD4 count	CD4 count range
Female	6	5	3	2	16	73	3-366
%	37.5	31.2	18.8	18.8	100		
Male	2	2	2	0	6	65.5	1-104
%	33.3	33.3	33.3	0	100		
Total	8	7	5	2	22	66	1-366
% total	36.4	31.8	22.7	9.1	100		

Fifteen female (78.9%) and six male (85.7) respondents were on ARVs at the time of the interview (81% of total sample). Two were not on treatment, two had interrupted due to side effects and there was one defaulter. There was a wide range for ARV treatment duration (Table 7). The mean for the whole sample was 11.3 months.

Table 7: Length of time the 21 respondents in the study had been on ARV therapy

	1-6 m	7-12 m	13-18 m	19-24 m	>25 m	Total	Mean	Median
Female (15 on ARVs)	5	4	1	2	3	15	11.3 m	10 m
Male (6 on ARVs)	3	1	1	0	1	6	10.7 m	7.5 m
Total	8	5	2	2	4	21	11.1 m	10 m

More than half of the total sample had been registered with Hospice for under a year (Table 8). A number were still requiring hospice care after more than three years. The majority of the male cohort had been patients for less than a year. The median care period for the whole sample was seven and a half months.

Almost all of the patients (96%) had been referred by Settlers Hospital or one of the local municipal clinics. No patients had been referred by doctors in the private sector.

Table 8: Number of months the 26 respondents in the study had been registered hospice patients at the time of the interview

	0-6 m	7-12 m	13-24 m	25-42 m	>43 m	Total	Median
Female	7	4	4	2	2	19	8
%	36.8	21.1	21.1	10.5	10.5		
Male	4	2	0	1	0	7	3
%	57.4	28.6	0	14.3	0		
Total	11	6	4	3	2	26	7.5
%	42.3	23.1	15.4	11.5	7.7	100	

Respondents all lived in a wide distribution all over Grahamstown East. Homes were mostly brick dwellings but some patients (19.2%) lived in mud houses. Half of the respondents lived in family homes but more females lived in homes they owned than the male respondents (Table 9). Only seven respondents had running water in their homes with most relying on a tap in the yard and one respondent using a tap in the street. Most patients had flush, pit toilets or bucket toilets in their yards with only 23% having flush toilets in their homes. Only one respondent did not have electricity in her home.

Table 9: Details of home ownership of 26 respondents in the study

	Own home	%	Family home	%	Rented home	%	Total
Female	6	31.6	8	42.1	5	26.3	19
Male	1	14.3	5	71.4	1	14.3	7
Total	7	26.9	13	50.0	6	23.1	26

5.2 Structured questionnaire

5.2.1 Language, reason for referral, name for GH and details of family care-giver

Most (88.5%) of the respondents always saw an isiXhosa speaking hospice sister when they accessed care at GH. Most patients (85%) were looked after by a member of their family. The majority of patients related their reason for referral to hospice to HIV infection, with some identifying other concomitant diagnoses (Table 10).

Table 10: Reason for referral to hospice for the 26 respondents in the study

Reason	Number	%
Because I am HIV positive	17	65.4
Because I have cancer	2	7.7
Because I have another illness	2	7.7
I am not sure why I was referred	1	3.8
Because I am HIV positive and have cancer	2	7.7
Because I am HIV positive and have another illness	2	7.7
Total	26	100

Of the total sample, only two patients reported consulting a traditional healer since their diagnosis.

Whilst more than half of the sample referred to GH by the name “hospice”, other names were also used, including “those that help us” (ngumncedi), “the place that people can get help” (apho abantu batuwan uncedo), “my home” (khaya yam) and “the healing place” (indawo yonyanga).

5.2.2 Palliative care needs

Patients were asked to report on a number of issues in the WHO definition domains of palliative care. Answers were recorded on a scale of 0 to 4 and related to issues experienced in the past three days. Answers 0: meaning no symptoms, complaints or worries, ranging to 4: meaning overwhelming symptoms, complaints or worries.

Pain, in varying degrees, and other symptoms were reported by two-thirds of the respondents, with two patients complaining of overwhelming pain (Table 11). A third of the sample reported having no pain or other symptoms in the last three days. There was a wide distribution of reporting on feeling anxious or worried about illness. Two thirds of respondents reported that they had felt anxious or worried to some degree in the last three days. There was a high level of worry around money and food, with more than a third of patients reporting overwhelming levels of worry about money and food matters.

Table 11: Reporting on pain, other symptoms, feelings of anxiety or worry about illness, worries about money matters and worries about food for the household experienced in the past three days for the 26 respondents in the study

	0	%	1	%	2	%	3	%	4	%
Pain	10	38.5	9	34.6	5	19.2	0	0	2	7.7
Other symptoms	10	38.5	6	23.1	7	26.9	3	11.0	0	0
Anxious or worried	9	34.6	5	19.2	7	26.9	1	3.8	4	15.4
Worry about Money matters	3	11.5	6	23.1	6	23.1	7	26.9	4	15.4
Worry about Food	7	26.9	4	15.4	5	19.2	4	15.4	6	23.1

1 – Not at all, 2 – Slightly, 3 – Moderately, 4 – Severely, 5 – Overwhelmingly

The majority of respondents had a faith (92.3%) but more than a third of these reported that their faith or their church played no role in their disease (Table 12). The rest of the sample reported that their faith or their church had varying degrees of importance in their illness.

Table 12: Role of faith or church in the illness if the 26 respondents in this study

No role	10	38.5
Insignificant role	3	11.5
Important role	7	26.9
Significant role	5	19.2
Overwhelming role	1	3.8
Total	26	100

5.2.3 Involvement in care decisions

Generally respondents felt that they had been involved in decisions regarding their care since their illness had been diagnosed with most feeling that they had been fully involved (Table 13). No patients felt they had seldom or never been involved.

Table 13: involvement in care decisions for the 26 respondents in the study

Yes, I have always felt full involved	22	84.6
Most of the time I have felt involved	1	3.8
I have sometimes felt involved	3	11.5
I have seldom felt involved	0	0
No, I have never felt involved	0	0
Total	26	100

5.2.4 Three biggest worries or problems

The three biggest worries or problems identified by the patients in the self-ranking section of the SQ (“what are the three biggest worries or problems you have today?”) were categorized into themes in line with the palliative care domains identified in the WHO definition of palliative care (Table 14). No problems or worries were identified in the spiritual theme. Emotional needs were not identified specifically, e.g. I am depressed, but rather in relation to a need in another theme, e.g. money worries or worrying about the care of children. The physical theme included the categories: symptoms, HIV related and treatment related responses. A total of 12 problems were

identified that related to the physical theme. Social and family theme problems included categories: concerns about care and support of children, family concerns and conflicts, family issues relating to finances and elements relating to care giving. A total of 16 problems were related to the social and family theme. Economic theme included categories: problems related to money, homes and housing, disability grants (DGs), jobs and employment, and food. A total of 26 problems were identified by respondents in this theme. The three identified themes, physical, social and family, and economic were ordered to reflect which in which theme patients reported most problems or worries and in which they reported least. A total of 54 different problems or worries were identified. Most problems were in the economic, followed by the social and family and lastly, in the physical theme.

Table 14: Themes in which patient identified problems or worries were experienced for the 26 respondents in this study and numbers of issues identified in each theme and category

Theme	No	Theme	No	Theme	No
1. Physical theme		2. Social and family theme		3. Economic theme	
1.1 Symptoms	4	2.1 Issues relating to financial support and care of children	8	Issues relating to money	12
1.2 HIV related issues	5	2.2 Family related issues	3	Issues relating to homes and housing	2
1.3 Treatment related issues	2	2.3 Family and finances	3	Disability grants	6
		2.4 Care giving	2	Jobs and employment	4
				Food security	2
Total problems identified in physical theme	11	Total problems identified in social and family theme	16	Total problems identified in economic theme	26

Specific elements in each theme were analysed alongside and included in the thematic analysis of the SSI.

The six most prevalent worries were ordered from the most commonly to least commonly occurring (Table 15). The most problems or worries were in the category relating to money, and three economic related categories were in the list of six most commonly occurring concerns. Half of all concerns raised were related to economic concerns and half of the respondents listed a money related issue in their list of biggest problems or worries. Three patients did not offer any problems or worries on the day of the interview.

Table 15: Categories most commonly occurring in patients' list of problems or worries on the day of the interview for the 26 respondents in this study

	Category	Number of issues identified
1	Money	12
2	Concerns relating to care and support of children	8
3	Concerns relating to DGs	6
4	HIV related issues	5
5	Jobs and employment	4
	Physical symptoms	4

5.3 Semi-structured interview

Seven patients completed the semi-structured interview, five female and two male respondents with ages ranging from 23 to 46. The mean age was 44.8 years. Only one female respondent was married and the random sampling resulted in a cohort with far fewer dependents (mean 0.42) than the average for the whole sample who took the SQ. The level of education for this cohort ranged from grade 8 to grade 12 with a mean of Grade 10.4. Four patients had DGs and three had no personal income. Five respondents lived in family homes and one each in their own or rented homes. At the time of the interview five respondents were on ARVs, one had a treatment interruption for side effects and one was being worked up. The mean duration on ARVs for the five respondents on ARVs was 8.8 months. Length of time respondents had been registered hospice patients ranged from 1 to 26 months with a mean of 10.8 months. CD4 counts ranged from 8 to 366 at admission with a mean of 102, and five were stage IV at admission to hospice.

A thematic analysis was carried out on data from the seven respondents who took the SSI and three major themes were identified (Table 16). The first theme dealt with the meaning of HIV infection for amaXhosa patients living in Grahamstown. The second theme dealt with ongoing palliative care needs despite the availability of ARVs. The third theme dealt with the partnership that developed between patients and hospice as patients sought to manage their HIV infection.

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Table 16: Themes, sub-themes and categories developed in data analysis

Themes, sub-themes and categories		
Theme 1. HIV meaning for amaXhosa HIV positive patients in Grahamstown	Theme 2. Palliative care needs are ongoing despite ARV therapy	Theme 3. Patient-hospice partnership in HIV management
1.1 Medical meaning	2.1 Current needs	3.1 Relationship with Hospice
1.1.1 HIV microbial cause	2.1.1 Physical	3.1.1 Palliative care interventions for people with HIV/serious illnesses
1.1.2 Serious illness	2.1.2 Economic	3.1.2 Therapeutic relationship
	2.1.3 Social and family	3.1.3 Overcoming perceptions about Hospice
	2.1.4 Emotional	
1.2 Loss	2.2 Palliative care outcomes (met needs)	3.2 Mobilising resources and networking
1.2.1 Health	2.2.1 Physical	3.2.1 Resources that Hospice mobilised
1.2.3 Position in family	2.2.2 Economic	3.2.2 Resources that patient mobilised
1.2.3 Economic security	2.2.3 Social and family	
	2.2.4 Emotional	
1.3 Responsibility and commitment	2.3 Unmet and ongoing needs	3.3 Effective communication
1.3.1 Personal	2.3.1 Physical	3.3.1 Communication of needs
1.3.2 Others	2.3.2 Economic	3.3.2 Information
1.3.3 ARV therapy	2.3.3 Social and family	3.3.3 Support
	2.3.4 Emotional	3.3.4 Involvement in decision-making
		3.3.5 Outcome of no effective communication
	2.4 Distress	3.4 Participation in collaborative decision making
	2.4.1 Relating to diagnosis of HIV infection	3.4.1 Patients had expectations
	2.4.2 Relating to life-long disease	3.4.2 Expectations of other health care providers
	2.4.3 Relating to unmet needs	3.4.3 Meeting expectations
		3.4.4 Previous experiences

5.3.1 Theme one: HIV meaning for amaXhosa patients in Grahamstown

This theme explored the meaning respondents gave their disease and this was examined in the light of three sub-themes: the paradigm within which respondents explained HIV infection, the losses respondents suffered and what responsibilities respondents had because they were infected. These were further broken down into a number of categories (Table 16).

5.3.1.1 Medical meaning

Respondents expressed the understanding that their disease was caused by a virus that was directly responsible for making them sick. Thus, the disease was placed within a medical paradigm that explained that illness was caused by the HIV. One respondent identified that HIV was treatable and could be managed with ARV therapy. A traditional or cultural world view was not identified by any of the respondents, either as a cause or as a treatment or management option.

- *“It means that I live with the HIV/AIDS virus but I can live more years if I take the treatment correctly”*

Respondents identified that they suffered from a serious, lifelong illness. For some this felt like a death sentence. Others could identify that treatment was available and that there was hope for improved health. Respondents described how they would need special interventions to deal with their illness.

- *“This illness [I am HIV positive] means that I am going to be sick for the rest of my life.”*
- *“To me it is like a death sentence. Every time I can’t stop thinking about it. When I take the treatment it’s better but my body is not the same anymore, it does not go back to its usual state.”*

- *“What I know about my illness is that I can live longer if I live a healthy lifestyle, take my treatment correctly, look after myself and take care of myself.”*

5.3.1.2 Loss

Respondents described how being HIV positive had resulted in a series of losses that diminished them in their own and their families' eyes. Primarily respondents lost their health, but they also lost their sense of identity within their family. The loss of economic security was expressed relating to the inability to work and the direct costs of having HIV infection.

- *“At home they do not involve me. When they do something they put me aside because I am sick. When there is a family gathering or traditional celebration they say, no this one is sick, so I don't know why they do this. I haven't been involved in many things.”*
- *“If I could get a government grant because I will never get the strength to work again.”*

5.3.1.3 Responsibility and commitment

Despite one respondent expressing that her diagnosis had felt like a death sentence, respondents did express a sense of hope. Commitment and responsibility to a healthy life-style and to ARV therapy was seen as a positive intervention that could influence prognosis and outcome and this demonstrated a level of control that was being taken back by the respondents. One respondent also demonstrated that he had engaged with his responsibility to others to protect them from infection.

- *“What I know about my illness is that I can live longer if I live a healthy lifestyle, take my treatment correctly, look after myself and take care.”*
- *“My illness means that I must be careful and make other people aware and careful about it.”*

5.3.2 Theme two: palliative care needs are ongoing despite ARV therapy

Theme two described the palliative care needs that respondents identified and the outcomes of addressing these needs, and the outcomes of unmet and ongoing needs and resulting distress (Table 16). Certain needs were unmet or ongoing and the consequences of these contributed to distress, which was noted to also have other contributing causes. These issues were identified for a cohort of patients who were able to access ARV therapy, five of whom were accessing treatment at the time of the SSI.

5.3.2.1 Current needs

Similar percentages of patients in both the SQ and SSI cohort were on ARVs and it was clear from data from the SQ that patients continued to experience pain and other symptoms, emotional distress and social and family problems despite being on ARV therapy. SSI results mirrored the results from the SQ but the open-ended nature of the questions in the SSI gave patients the opportunity to express their needs more clearly.

Physical needs not only related to current symptomatic illness but demonstrated the ongoing nature of HIV infection. Respondents identified that their disease was chronic and that they would need treatment, support and medical care, not only to deal with a disease with no hope of cure, but also to manage life-long ARV therapy. One respondent in the cohort suffered from other concomitant chronic conditions that added to treatment burden.

- *“To me it is like a death sentence. Every time I can’t stop thinking about it. When I take the treatment it’s better but my body is not the same anymore, it does not go back to its usual state.”*
- *“What if I become really ill again?” (SQ)*
- *“I have a lot [of problems]. Firstly I am HIV positive, secondly I am diabetic and thirdly I have high blood pressure. All these illnesses together add*

more pain, like today its painful here and tomorrow it's painful somewhere else. This means all the time there is pain somewhere in my body."

- *"I am worried about the treatment I am taking now [ARVs] and their side-effects."(SQ)*
- *"I want to get back on my ARVs." (a defaulter) (SQ)*

Economic needs were identified against the socio-economic context defined by the demographic data. Economic needs reflected patients' socio-economic status and illustrated how economic needs influenced feelings of depression and distress. Main concerns related to grants, jobs and employment, housing and having enough money. These underlying economic issues were overlaid by the influence of HIV on earning ability and the extra costs that may be related to the disease itself. Problems relating to lack of money, or concerns about grants were repeatedly mentioned in association with distress.

- *"As I said I am very depressed, if I could just get a government grant."*
- *"As I have said, what I need is to be employed and earn money."*
- *"The help I need is to have enough money to be able to cater for all the needs I have concerning my illness."*
- *"My grant is expiring and what will I do for money?" (SQ)*

A number of social and family needs were identified relating to care of children, family cultural practices, family conflict and care giving concerns. It was obvious in the analysis of the problems and worries from the SQ that concerns regarding care and financial support of children were very common for the 26 respondents who completed the SQ. This was not as obvious in the SSI data, however it has been noted that the SSI cohort had a much smaller mean for dependent numbers. One respondent noted that she was worried about what would happen to her child if she died and she worried about how to support him.

- *“I feel sad and I am scared what if something happens. I think what if I go to sleep and not wake up? What will happen to my youngest child that is in the boarding school?”*
- *“I cannot afford to pay school fees for my child; he is in a boarding school. I only paid registration fees only. I never paid the rest of the money and that makes me feel guilty, it’s like I have dumped him to the school.”*
- *Who will look after my children if I am gone [die]? (SQ)*
- *I am worried about not seeing my baby growing up. (SQ)*

Both the male respondents expressed concerns about family related cultural practices that they had been unable to participate in due to their illness.

- *“I wanted to attend ukubuyisa (sending away) and ukukhapa (bringing back) rituals [but I was too ill].”*
- *“The only problem that I have is that I didn’t go to my dad’s uvasha imihlakulu ritual(washing of the spades - burial ritual). That’s the only problem that bothers me.”*

Family conflict was more clearly demonstrated in the SQ problems and worries list and was not as evident in the SSI. One respondent, however, described how she had been stigmatized and rejected within her own family.

- *“My parents are fighting with me about my status.” (SQ)*
- *“My brother won’t support [financial] his children who live with me.” (SQ)*
- *“My mother didn’t accept that I am HIV positive until she died, only to find out that she was also HIV positive. She didn’t even want to touch me. That was very painful to me, I was hurting.”*

It was clear that respondents relied on their families to take care of them when they were ill and one respondent related how a neighbour cooked and cleaned for her when she had been very sick as she did not have family to assist her. Respondents in the SQ

who did not have family expressed concern about who would look after them if they needed care but this was not as clearly expressed in the SSI.

Two thirds of the total sample had reported being anxious or worried to some degree in the past three days, but it was noted that direct emotional needs had not been identified in the SQ problems or worries list. Emotional needs were more evident in the SSI cohort as the open ended nature of the questions allowed respondents to express their emotional symptoms and problems more clearly. They demonstrated feelings of depression and stress, they felt alienated and isolated, and some reported feeling overwhelmed and hopeless. Emotional distress was often referred to in association with financial issues where financial pressure and lack of money was the cause of the emotional distress.

- *“I am very depressed, if I could just get a government grant.”*
- *“I realised I am alienated, that is people are avoiding me.”*
- *“I can’t handle all these problems; I have been having them since I fell ill. I can’t handle them. “*
- *“I think about going to the physiotherapist but at the same time you go there and complain about a shoulder and it is treated, the following day it’s another part of the body. That makes me give up and just leave it.”*

5.3.2.2 *Palliative care outcomes*

When respondents felt that their palliative care needs had been met, they experienced improved health, felt supported, assisted and cared for. Needs were met in a variety of ways by a range of people and services. The most obvious outcome of palliative care and ARV access was improved symptom management and improved health.

Respondents noted how their relationship with GH had provided support and assistance and enabled them to access resources. Met needs were described in the physical, economic, family and social and emotional domains.

Met physical needs resulted in pain and symptom control and improved health. Respondents noted how their health had improved while on ARVs and their ability to access ARV therapy and beginning treatment was an important intervention to address physical palliative care needs.

- *“I was wheelchair bound, couldn’t do anything, now I can walk.”*
- *“My illness started in June. I had pneumonia and I was tested. I was confused not knowing what is going to happen, not knowing the results. I was told that I am HIV positive. I lost weight, couldn’t sleep and couldn’t eat properly, living with water only. I went back to hospital and I started using ARV’s and I was told that my CD count is 12. I started eating it [taking ARVS] in October and I took care of myself but there were days when the treatment made me dizzy. I had TB for 2 months and it was very serious. I got better and my CD4 count now is 223.”*

While respondents identified many economic needs, and these were also very evident from the SQ data, it was clear that these needs were more difficult to meet. The limits within which GH as a service provider could address real economic distress were obvious with help being limited to assisting patients with the grant application process and to provide clothes and food parcels.

- *“[Hospice] helps me with food.”*
- *“They applied for a grant for me, it was successful and I am still receiving it.”*

Social and family needs relating to concerns about children and various sources of family conflict were clearly identified in the SQ list of problem and worries, but how GH was able to intervene to address these needs was not clear. One respondent explained how she had been rejected by her mother and she had sought hospice intervention in an attempt to resolve the conflict.

- *“My mother didn’t accept that I am HIV positive until she died, only to find out that she was also HIV positive. She didn’t even want to touch me. That*

was very painful to me, I was hurting. I told the nurses that my mother doesn't want to accept me. They sat her down and spoke to her but she still refused to accept me and she died later."

Respondents had identified many areas of emotional need and expressed how hospice had engaged with them to offer support. There was a sense that being and feeling accepted and heard was an important element of dealing with emotional need

- *"It's [Hospice] a home for those people who are very ill and can't do anything for themselves and it plays a role of helping those people heal and be able to walk again. There are females that you can talk to about anything that is bothering you. So I call it a Home."*
- *"They help me because sometimes I am in the township, they come to my house and I have a chance of telling them what bothers me. Some days I don't have a chance to go to the clinic and they help by bringing what I need at that time and I sit with them and chat. You know, it is nice to open up to someone about what bothers you and you feel relieved as if something has been taken off you. So that is how they help me."*
- *"No, I haven't got help yet but I did speak to them about these problems because speaking about them makes me feel relieved inside even if they do nothing about them."*

5.3.2.3 *Unmet needs*

Some needs were unmet. These occurred across the palliative care domains. The chronic nature of HIV infection resulted in varying degrees of ongoing physical symptoms. Palliative care generally and GH specifically were unable to address many of the economic needs patients experienced. One patient experienced her social and family pressures to be overwhelming. The SQ revealed that mothers worried a great deal about the long term care of their children. While this was not as evident in the SSI for the reasons postulated, concerns were expressed relating to the emotional and

financial care of children should mothers die. Linked to this were concerns expressed by patients who had been ill, had accessed ARVs and were well, should they become sick again. Some respondents expressed insight that they had certain problems that GH was unable to solve.

- *“I can’t handle all these problems [family issues].”*
- *“I think they didn’t have a way to help me so I have to see what to do about the situation. As for them they couldn’t find a way to help me because truly I spoke to them about my problems.”*

5.3.2.4 *Distress*

There were layers of distress that respondents experienced as they dealt with their HIV infection. These were firstly associated with the diagnosis and lived experience of HIV infection and respondents noted the losses, stigma, isolation and family conflict that they experienced. Secondly distress was related to dealing with and managing a life-long disease for which there was no hope of cure. Thirdly, unmet needs, both those that could not be addressed and those that were not communicated, contributed to distress. These issues have been referred to previously, underlining the complex relationship between specific needs and resulting distress.

- *“This illness means I am going to be sick for the rest of my life.”*
- *“As I said I am very depressed, if I could just get a government grant.”*
- *“I haven’t been helped because I have never spoken to anyone about it.”*

5.3.3 Theme 3: Patient - GH partnership in HIV management

In theme 2, respondents described the needs that related to their illness and how these needs had been met. Theme 3, which related to patient-GH partnership in HIV management, examined the outcomes of this relationship as Hospice engaged with respondents to network and mobilize as many resources as possible to address the many and varied problems these HIV positive people experienced (Table 16). It also

examined the central importance of effective communication. When patients felt involved and informed, collaborative decision making between patients and the agencies involved in their care became an important outcome.

5.3.3.1 *Relationship with Hospice*

The relationship with GH gave people access to palliative care to assist them with managing HIV infection and other serious illnesses. GH was also identified as a source of support for patients who were on ARVs as this therapy was, at times, difficult. The relationship respondents forged with GH was supportive and accepting, even if problems could not be solved or if respondents could not express their needs.

- *“It’s a home for those people who are very ill and can’t do anything for themselves and it plays a role of helping those people heal and be able to walk again.”*
- *“The help I received from my [Hospice] sister is that she cared for me, trying her best to support me in many ways, because, I even wanted to stop taking the ARV’s and preferred to die because of what was happening in my body at the time I started taking them.”*
- *“No [I haven’t discussed these problems with Hospice staff but] they help me by visiting me and giving me advice.”*

One respondent had to get over her preconceived ideas and perceptions regarding Hospice before she was able to engage with them as a source of support and care.

- *“As I have said, it means a home because at the beginning when you hear Hospice they mean Death and there is no hope if you go there you are going to die. I have full blown Aids and I convinced myself that I am going to die. So through Hospice I managed to get up.”*

5.3.3.2 *Networking and mobilizing networks*

A number of resources were mobilized as problems and issues were addressed and dealt with. Some of these were resources that patients themselves mobilized and some that GH was able to mobilize on a respondent's behalf. Both GH and respondents used their networks within their spheres in this process. GH was able to assist with accessing medical resources, help respondents with grant applications and assist with the practical issues of physically getting to medical care.

- *"I was taken [by Hospice] to a scan to find out what was inside"*
- *"It is because when other people are treated and examined, I am also treated."*
- *"They applied for a grant for me, it was successful and I am still receiving it."*
- *"Yes, because [when] have a doctor's appointment, they come and take me to Hospice so I can see the doctor."*

Respondents mobilized support when they accessed medical care from the hospital, local clinics and the ARV service, and from family and community members.

- *"Now I am living knowing even if I don't feel well, if I go to the municipal clinic, they help me and if there is something else bothering me I go to Dr. D [at Masonwabe clinic]. She will sit me down and we'll chat if there is anything worrying me at home. They always tell me what to do. Everything is going to be fine. Every time I go to the [ARV] clinic I feel better and know that I am having a good day. I feel okay when I am with Dr. D because I tell her about how the treatment treats me. I feel accepted and it is nice. Otherwise I am okay."*
- *"It is the hospital [that has helped me]."*
- *"My mother [helped me and] visited me when I was admitted to Santa [TB Hospital]."*

- *“My neighbour cooked for me, cleaned my house and also took me to the clinic.”*

5.3.3.3 *Effective communication*

It was evident that effective communication determined the reporting of needs, how information was imparted, and how respondents experienced support and comfort. Respondents who felt that they had been involved in decision making noted that explanation and information was an important element of this.

- *“I say that because when I go to the clinic or I meet a person from Hospice, I ask that person about my illness, he / she gives me the response that I need and makes me feel satisfied.”*
- *“They visited me and I speak to them about anything that I need from them. They explained and informed me about my illness, sometimes they help me there and there, telling me what I should do or not.”*
- *“I am informed about everything. When they want to do something to me, they ask how I feel about it.”*

When communication was not effective patients were unable to communicate their needs. An important barrier to meeting needs was a lack of communication.

- *“No I never discussed them. I never went to them that is why I could not be helped.”*

5.3.3.4 *Partnerships in collaborative decision-making*

The degree to which respondents felt that they had been consulted and informed about decisions regarding their medical care was explored. This was against the background of respondents' expectations and previous experiences. This related again to effective communication. Patients expressed that they had expectations of GH to help them,

they had expectations of other health care providers in the town and they felt that these expectations had generally been met.

- *“I got it from the hospital because I don’t have short-breath anymore and I can eat now. I can walk again because I couldn’t walk; my legs were weak, now I can because of the hospital.”*
- *I was sleeping at [the] Palliative Care [ward], my [Hospice] sister and the Social worker came and asked me if I would love to go to Hospice. They explained what the Hospice is all about and I was very happy because I knew that I am going to be with people that are going to help me, people that I will speak to about anything that I want to say.*

There was an underlying suggestion that some patients had had previous experiences where their expectations had not always been noted or met.

- *“It is because when other people are treated and examined, I am also treated.”*

This was most evident for one respondent who related her experiences in another city.

- *“I asked them how come they do all these things without informing me. How can they make such decisions? I became a bad person for asking and that was another pressure on me.”*

5.4 Summary

The process of assessing reliability and validity was continued as data from all three data sets were analysed and compared to each other.

Summary analysis: The demographic data located the respondents geographically and described their residential status. The cohort had low levels of education, limited financial resources and no respondents were accessing private medical care. The minority of patients was married and the majority was looked after by family members. All of the respondents were HIV positive and accessing palliative care and the majority was on ARVs. Despite this, three quarters of the patients experienced pain, other symptoms, distress and anxiety in the three days preceding the interview, and these needs were explored in more detail in the SSI. However, respondents did not appear to find these issues particularly worrying as they did not rank ahead of either financial or family and social issues in the self ranking in the SQ. The financial issues evident in both the SQ and SSI were seen against the background of the context described by the demographic data. Financial issues ranked as the most prevalent problem or worry. Met needs were described as outcomes of palliative care, and unmet needs added to the distress respondents experienced.

This cohort described the meaning that HIV infection had for them and this reflected their lived experience of being HIV positive within the described context. Respondents valued their relationship with GH as a partner in managing their HIV infection and described how GH engaged with them to meet their needs in a collaborative way that relied on effective communication to mobilize a variety of resources.

CHAPTER SIX

6. Discussion

In examining the context and palliative care needs of isiXhosa speaking HIV infected patients accessing palliative care from Grahamstown Hospice, this research project firstly considered the interplay between the person, their context, needs that resulted from HIV infection and the resources patients had at their disposal. Secondly, it examined the dynamics that determined the addressing of needs to explore how respondents perceived their needs to have been met, unmet or remain ongoing. Lastly the role of Grahamstown Hospice as a provider of palliative care was scrutinized to review patient expectations of Hospice, demonstrate if and how effective hospice based palliative care was in addressing palliative care needs and to consider if respondents felt involved in collaborative decision making regarding their care.

6.1 The person and his or her context

The literature review suggested that context was an important consideration in the access to and provision of palliative care for HIV positive patients. ^{16 17 20 64 65 66 44 45}

The importance attached to context is multi-focal as it not only describes the situation in which patients find themselves as they experience life-threatening illness, but it also ensures that both assessment of needs and care offered is patient centered and holistic. In addition, context informs the personal, family and community resources accessible to a patient.

Study respondents were geographically situated in Grahamstown. All twenty-six respondents were unemployed, isiXhosa mother tongue speakers with no tertiary education. They were all HIV positive and the majority was on ARV therapy, and all were accessing palliative care through GH. Three quarters of the respondents in the study were female.

Most respondents were living in households not made up of western traditional nuclear families and this was consistent with the social and cultural context of the study population.^{54 55 58} Household numbers for this sample were very similar to those quoted for this population group in the 2001 census of Grahamstown³³ and Kelly and Ntlabati's cohort from the same town³². Most patients reported that they were looked after by a family member, but evidently this person was not a spouse. The data suggested that mothers were an important resource to provide for care and support and this is later extended to orphaned children if their mothers died. It was noticeable that more women than men in the sample reported that they had dependents. The men who did have dependents had, on average, fewer than the women in the group. This is important as it may not necessarily reflect that these men have fewer children, but rather that they are not involved in their care.

This pattern of few married individuals, mothers caring for sick, adult children, the presence of non-traditional nuclear families living together, and men/fathers' not actively involved in care, was considered to reflect an underlying cultural and social dynamic that was relevant in defining context. This was supported by the literature.^{54 55 56 60} The smaller number of married individuals in the cohort was thought to reflect both a cultural and economic reality as poorer men would be less able to raise bride price and thus be less able to marry. This in turn would result in maternal grandmothers' and mothers' extended families becoming responsible for orphaned children as they would not be considered to be part of their fathers' families. Kelly and Ntlabati³² suggested in their 2007 paper that there were already in the region of 700 orphans in the Makana Municipal area who had lost one or both parents.

The implications of caring for orphaned children are not limited to South Africa⁶¹ and have been described in other parts of Africa.⁶² This is important both as a response to and an outcome of young people dying, but it also heightens the risk of crisis and conflict within families with extra care-giving burdens. Male family members did not appear to be occupying care-giving roles either to ill adult female family members or to

children. This was echoed by Demmer⁷⁶ who suggested that men should be encouraged to become more responsible for care-giving. It may be very difficult for men to move into more traditional female roles. Some entrenched stereotypes will have to be broken down to enable men to be recognised as supportive, responsible and able care-givers.⁵⁸

Respondents described how household composition had been influenced as a response to HIV infection, as this was superimposed upon a system where resources were shared amongst kin⁵⁶. There was, however, tension resulting from this added burden, particularly if the children who were being looked after had a surviving parent who did not contribute financially or otherwise to the household. Women shouldering this extra burden experienced distress if they felt emotionally and financially unsupported. Female respondents did not perceive the fathers of their children to be a reliable source of social or financial support and this exacerbated their distress relating to potentially life-threatening illness and the possibility of orphaning their children. This dynamic was noted by Hosegood et al⁵⁹ who described a significantly smaller number of children who could be linked to their fathers, compared to those who could be linked to their mothers, and Montgomery et al⁵⁸ who reported on men's care-giving roles in HIV affected households.

Thus it was clear that despite the difficulties that were described, respondents relied heavily on their families for physical and emotional care, housing and financial support and this constituted a significant resource. However, even though kinship was an important element that protected people from abandonment in ill-health, there were patients who did not have family to take care of them and this caused distress.

In the 2001 census, only a third of the Grahamstown's African/Black population in the working age group were employed.³³ This implied that even had the cohort been healthy, employment opportunities would have been limited. Respondents had no tertiary education and jobs, employment and money related issues were clearly

significant. Financial issues were further evident as there was financial pressure not only on these sick individuals, but also on households as a whole. Some households relied on a single income from within the household and sometimes on financial support from an outside source. There was a high level of focus and reliance on social welfare grants and respondents repeatedly raised concerns about grants. Failure to be deemed eligible for a grant or an expiring grant was cause for distress and anxiety. Patterns for household income and social welfare grant access for this cohort were very similar to those of Kelly and Ntlabati's³² sample, suggesting that this cohort, although small, reflected the economic status of the community in which they were living in Grahamstown. Other authors have noted similar patterns of low levels of employment and poverty experienced by HIV positive people and their families in other parts of the country.^{15 79} Financial pressures for HIV positive patients and families have also been reported in other parts of Africa.^{64 65} Bachmann and Booyesen⁷⁹ observed that households with an HIV positive member were on average larger, poorer and had fewer employed householders than unaffected families.

In 2007, when this data was collected, social welfare grants were as follows: old age pension (OAP) – R840, child support grant (CSG) – R200, foster care grant (FCG) – R540 and disability grant (DG) – R840. None of these grants constituted a living income as an income of below R800 per month is considered to be the ultra-poverty line.²⁹ Twenty percent of households represented in the cohort were dependent on the respondent's DG. Respondents did not appear to experience DGs as long term, stable sources of income and were concerned about accessing and retaining grants. Against the background of low levels of education, limited employment opportunities and ill-health, the preoccupation with social welfare grants is understandable as respondents had limited access to financial resources. This also supports the notion that ARV therapy and social welfare support for the poor should be complementary policies in the fight against HIV/AIDS in South Africa.⁸⁰

Only a third of the respondents lived in homes they owned and less than a third of respondents had inside running water or flush toilets. As the demographics of these respondents and Kelly and Ntlabati's³² cohort are similar it is likely that respondents in this study experienced similar difficulties with access to municipal services. It would appear that it may be necessary for social welfare support to also make provision for adequate access to basic municipal services and housing for those affected by and infected with HIV.

The spirituality and traditional belief systems of the amaXhosa have been described. Within this paradigm illness may be seen as manifestation of punishment of wrongdoing and not be explained within a western scientific or medical paradigm. The conflict between a traditional and medical explanation of HIV infection has been noted.^{49 52 51} As a result patients may consult a traditional healer to determine ultimate causes of illness and a western, medically trained doctor for proximate causes, pain and symptom management.⁴⁹ The role of traditional healers is to divine the reason for ill-health.⁴⁷ Most respondents in the sample reporting that they had a faith, but only two respondents reported that they had consulted a traditional healer since their diagnosis. Respondents did not raise concerns regarding ultimate causes of their illness and appeared to explain their infection within a medical paradigm that explained and accepted a proximate cause of their disease as an infection by the HI virus.

It was however anticipated that patients would under-report consultation patterns with traditional healers as the researcher was not a member of the same culture group and was a Western trained doctor. Patients may have been uncomfortable in discussing their traditional belief systems with medical personnel, especially if they feared stigmatization or were concerned that medical care may be withdrawn if they wished to consult with a traditional healer.

The pattern of consultation with traditional healers and the ease with which patients appeared to accept a medically grounded proximate cause of their HIV infection was

seen alongside high levels of reporting of having a faith, but low levels for the importance of faith in their illness. These factors suggest that this cohort have grounded their illness, not in a traditional paradigm of malevolent ancestral influence where ultimate causes of disease is important, but rather in a medical microbiological paradigm that explains proximate causes. This finding is in contrast to other studies that suggest that both co-exist.^{52 53} It has been proposed that AIDS related beliefs are mediated by knowledge⁵¹ and these findings support this idea, suggesting that over time, HIV education and experience results in individuals becoming comfortable with a proximate explanation for HIV infection.

The context of this group of patients was explored and it was against this background that individuals became infected and live with HIV. There was understanding and acceptance that HIV infection is life-threatening. Interventions were recognised that could improve quality of life and offer the hope of the long term chronic management of a potentially life-threatening infection. Respondents also noted that HIV infection required them to be responsible about their health, their treatment, and for others around them. Despite the hope offered by ARVs and help offered by palliative interventions, respondents experienced loss. The illness diminished respondents in their own eyes and in the eyes of their families. This sense of loss appeared to occur despite ARV access. While the focus of the rollout programme is wide ARV access, it must be noted that all individuals who are diagnosed HIV must be expected to experience distress related to loss, and this is an important area where support that can be offered by palliative care providers in the ARV era.

Context and lived experience position individuals who, in order to deal with HIV infection, have to be able to access and mobilize resources. Household, social and financial resources were described for this cohort, and patients clearly relied heavily on their families. But strong family resources contrasted with limited financial resources and no respondents in the study were able to access private medical care in Grahamstown. The town's state managed medical services (hospital and municipal

clinics) constituted patients medical resources and the free service offered by GH meant that this group was able to access palliative care, which included treatment support, to restore a level of health.

6.2 Needs

The literature review suggested that context was important to palliative needs and palliative care provision.^{16 17 63 64 65} This group of patients was identified and positioned within the context described. Palliative care needs were explored against this backdrop to reflect the interplay between context and palliative care needs, and to demonstrate that the focus is on the person within a context who is HIV infected, rather than merely focusing on HIV infection in a patient.

Needs were explored in the domains: physical, emotional, social and family, economic and spiritual. ARV therapy was being accessed by eighty percent of the group and while half of the cohort had been receiving palliative care from GH for less than a year, two patients were still requiring care after three years. More than two thirds of this cohort had active symptomatology to some extent in the three days preceding the data collection. These results are consistent with other studies that suggested that symptoms persist despite ARV therapy.^{68 72 73} Physical symptoms did not feature in the self ranking of needs. The issues that were identified in the physical domain of the self ranking relating to HIV infection were associated with status and concerns about long term health. Newly admitted patients reported more physical symptoms, particularly pain, but did not rank these as their most worrying concerns. It appeared that while respondents did have active symptoms, these were not particularly worrisome and respondents demonstrated an acceptance of these as part of the challenges of dealing with a life-long chronic infection for which there was no cure. This may relate to the improvement in general health and well-being that patients experienced on ARV therapy as respondents compared their current health to their health status prior to ARV initiation, and this allowed respondents to address other issues. Some respondents had

other medical problems like hypertension, TB or concurrent malignant diseases and these added to symptom burden. Thus, despite a mean ARV treatment duration of 11 months, patients continued to experience symptoms. It was clear, however, that in overall self ranking of problems, physical issues were outranked by other concerns. Importantly, patients' needs were not only related to current physical symptoms, but included a need for education and information about ARVs and the support required to commit to lifelong ARV therapy.

Economic needs were very evident for this cohort. More than a third of respondents reported severe or overwhelming worry about money or having enough food for the household, and these figures were similar for Kelly and Ntlabati's³² Grahamstown cohort. This predominance of economic needs was echoed in data from other African countries.^{64 65 66} Economic issues abounded in the self ranking of problems or worries and three of the top ranked issues were economic related. There was a great deal of distress associated with these concerns and patients experienced this as anxiety and depression. One respondent identified that her illness itself had worsened her economic status and that managing HIV infection placed a financial burden on her. It has been noted that poor people are more likely to become infected and that the affected become poorer.^{77 79} This study design did not address the direct effects of HIV on economic status at personal or household level but the preoccupation with matters financial was considerable and these affected households can be expected to become poorer.

It is relevant that economic needs, by their very nature, are difficult to address directly by palliative care interventions, which cannot provide social welfare, and may be limited in interventions to improve levels of education or unemployment community-wide. However, many hospices do offer vocational training and support income generating programmes. These findings highlight interaction between the economic context of individuals and needs, as respondents identified the impact of limited financial resources as an important cause for distress.

The social and family related issues reported by respondents were explored against the demographic background described. There was evidence of strong family support in care-giving but there were concerns when there was unreliable or unavailable family support. The economic pressure felt by individuals and families also contributed to stress and conflict in families. Respondents raised issues that reflected experienced stigmatization, isolation and denial within their families related to their HIV status. HIV positive individuals appeared to experience a tension between significant reliance on their families on the one hand, and vulnerability to stigmatization, denial and isolation when they disclosed or needed care on the other.

Needs experienced in the social and family domain were also influenced by the social and cultural dynamics of respondents as respondents did not appear to rely on their spouses for care and woman appeared to shoulder most of the care giving burden. The men experienced distress when they were unable to participate in cultural rituals as the men are custodians of social and cultural norms and rituals within this amaXhosa cohort⁴⁷. It was also clear that within this cultural background, men had more difficulty discussing their needs with female Hospice workers and this limited the potential for palliative intervention. These findings emphasize the importance of understanding the social and family dynamics of palliative care patients as these influenced resources, suggested areas for special interventions, and considered areas of potential distress and conflict within families.

Anxiety and depression were far more commonly associated with concerns relating to food security and financial issues and less likely to be reported as a primary symptom. This was particularly evident in relation to social welfare grants, where respondents directly reported that if grants could be accessed and financial security be guaranteed, anxiety, worry and depression would be resolved. Clearly this distress did not appear to have been lessened by patients being able to access ARVs or experience improved physical health. It was unclear if the prominence of distress related to economic pressure resulted in the under-reporting of physical and spiritual issues in a Maslow-

type hierarchy of identifying needs. There was a noticeable lack of identified spiritual needs and respondents did not appear to identify their church or church community as an important resource to help them when they became ill and needed assistance. The reasons for this were not explored.

Thus for this cohort of HIV positive patients accessing palliative care there appeared to be a predominance of economic needs and these preoccupied respondents more than their physical or other needs. Physical needs persisted to some extent despite ARV access but did not appear that troublesome to patients, and were more evident for newly admitted patients. Emotional needs were significantly influenced by economic pressures and limited financial resources also mediated tensions within families. Clearly a wide range of needs persisted despite ARV access and patients continued to require palliative intervention for a significant period of time.

6.3 Outcomes of palliative care interventions

6.3.1 Met needs

The intention of palliative care is to address pain and suffering, thus the needs identified were explored further to allow patients to describe if and how needs had been met. It must be noted that the description of met needs related to respondents' observations and not to data derived from reliable and validated observer-rated or self-report instruments. Respondents identified that needs were met in a variety of ways and by employing a variety of strategies and resources. It was difficult to separate the effects of ARV access and of palliative care access as most of the study participants were accessing both concurrently. It was clear that patients reported an improvement in their physical health and that Hospice was seen as an important asset to access medical resources.

Few economic needs could be met by GH directly and this drew attention to the wider educational and economic needs of this group of HIV positive patients that were related to their socio-economic status. But food parcels and clothes from GH were gratefully received. The data did not clearly describe how family needs had been met by GH despite the description of a number of family related issues. It was also not apparent how GH addressed the issues related to orphans and vulnerable children (OVC) and the concerns of mothers regarding the long-term care of their children should they die.

Met emotional needs resulted in respondents expressing a sense of being cared for and supported. Respondents felt supported even if needs were not met, and they also felt supported even if they did not directly express particular needs. This suggests that GH, and thus palliative care intervention, was beneficial to patients simply by virtue of their contact and that GH appeared to be seen as an ally against the difficulties of facing HIV infection. It was noted that patients did not report specific interventions for depression or anxiety, such as psychotherapy or anti-depressants.

Thus needs were being met, but the physical needs of patients appeared to be most easily and effectively met. It was clear that needs in other domains were more difficult to address. Harding et al²⁸ note that most improvement from palliative intervention for HIV positive patients is in the areas of pain and symptom management, anxiety, insight and spiritual well-being and this supports the results from this study, with the exception of spiritual well-being. However, even if specific needs could not be met, patients still felt supported and cared for if they were accessing palliative care from GH.

6.3.2 Unmet needs

The intervention of GH and palliative care did not meet all the needs that patients experienced. Needs were ongoing in line with the challenges of chronic illness and persisted despite ARV access. Unmet needs were also reported across the palliative care domains but economic needs were most obvious. Respondents understood that

certain of their needs could not be met by GH as they did not have the resources or ability to address certain, mainly financial, issues. Respondents also understood that problems could not be addressed by GH if they were not communicated. It was of particular concern that certain needs of the male patients appeared to be unmet as they were reluctant to disclose these to female staff members. A number of respondents expressed “what if” concerns and this implied that addressing patients’ needs should consider not only the needs that patients experience today, but also those things that they fear may happen in the future. Clearly needs continue despite ARV therapy and this is supported by other authors.^{28 73}

6.3.3 Distress

The distress patients experienced was not only related to the unmet needs of the day, but also reflected the complexities of managing a lifelong illness with no hope of cure and issues associated with the diagnosis of HIV and related stigma, isolation and loss. This supports the notion that palliative care remains relevant to HIV positive patients throughout their disease trajectory from diagnosis, through ARV access and in death and motivates for the provision of care even when patients on ARVs experience clinical, immunological and virological success on ARV therapy. It was clear that unmet needs, whatever their nature, caused distress in themselves, and that the resulting distress became another need if it manifest as depression, anxiety, isolation or stigma.

6.4 Positioning of GH as a partner in managing HIV infection

HIV positive people have been demonstrated to have palliative care needs and these needs continue throughout disease trajectory and appear to persist despite ARV therapy access. Patients either self-accessed palliative care or were referred by a healthcare facility, and it was clear that they had expectations of assistance. It is within the framework of these expectations that GH is positioned as a resource to help patients deal with life-long and life-threatening HIV infection.

HIV positive patients accessing palliative care from GH entered into a relationship with GH. This relationship provided help and support in the face of life-threatening illness and when patients embarked on the challenges of committing to long-term ARV adherence. The relationship was therapeutic as it had benefit for patients who felt supported and cared for even if specific issues could not be addressed or solved. There was evidence that patients sometimes had to overcome their preconceived ideas about GH and what hospice care meant before they could engage with the care that could be offered, thus removing this internal barrier to care. Kelly and Mzizi³⁵ describe an external barrier to care in reference to Grahamstown when they noted that some patient's fear stigmatization and disclosure if the GH hospice car is parked outside their home.

It was crucial that HIV positive people were able to mobilize a variety of resources as they sought to deal with their illness. While respondents appeared to successfully mobilize a number of effective family and community resources, GH as a partner in care made other resources more accessible. Patients implied that their relationship with GH made medical care more accessible to them and GH could act as an interface with other medical resources in the town.

The role of effective communication was crucial as it determined how respondents expressed their needs, how supported they felt, and determined if they had felt involved and participant in the decisions that had been made regarding their care. HIV positive patients in the developed world have been reported to need support and communication from their physicians as part of their medical care⁶⁹ and these findings suggest that this need is not exclusive to the physicians patients engage with, but is important for all members of the multi-disciplinary team. Ultimately communication determined if respondents had been partners with their health care providers in a collaborative decision making process.

The benefits of effective communication in the palliative care setting are that needs are met, distress is reduced and quality of life is improved. Clearly if needs are not communicated they cannot be addressed. Effective communication also reflects on the patient centeredness of the care provided. In addition, effective communication and collaborative decision making suggests that patient care is being undertaken in an environment that respects patient autonomy and is addressing the beneficence and non-maleficence of any proposed interventions. Some of the respondents in the cohort referred both directly and indirectly to previous experiences where they had not felt involved and had been marginalised or dismissed. This cohort reported a high level of involvement in decision making both by GH and other medical services they accessed in Grahamstown. Access to health care is accepted as a basic human right and this cohort of patients in Grahamstown demonstrate the outcomes for patients who are able to access health care, ARV therapy and palliative care concurrently in an integrated health care system.

6.5 The interplay of individual context, resources, met and unmet needs and GH as a provider of culturally sensitive palliative care

Palliative care is universally relevant, but how each person experiences life-threatening disease is individual and context specific. An HIV infected person experiences needs within his or her context and these needs are met by mobilizing a variety of resources accessible to the patient. One of these resources may be a palliative care provider who operates within a certain set of constraints or limitations that may also be influenced by context specific restrictions that are determined by the capacity of a particular community.

This group of HIV infected people living in Grahamstown demonstrated how context influenced their personal resources, both positively and negatively and how these mediated experienced palliative care needs. The cultural context of these patients influenced family and social dynamics and resulted in strong social and family support

but increased the potential for conflict related to limited financial resources and the pervasive power of stigma. The lack of financial resources, limited employment opportunities and education resulted in a dominance of economic needs that overwhelmed the continued physical problems of a life-long, life-threatening illness, and were a significant cause of emotional needs. GH was an important resource available to HIV positive people living in Grahamstown, however, GH operated within its own set of constraints, and had a limited ability to address the fundamental aspects of poverty affecting this cohort. In this respect, the context of GH itself indirectly influenced respondent needs.

HPCA has demonstrated its commitment to the provision of culturally sensitive care and guidelines are clear in the HPCA/ Council for Health Services Accreditation of Southern Africa (COHSASA) Hospice Palliative Care Standards.¹⁰¹ This study attempted to place its cohort within a context to consider how this would impact upon the needs patients' experienced, and to comment on how needs had been met by the palliative care provided by GH. GH is fully accredited by COHSASA with a five star rating which considered a number of areas that addressed the provision of culturally sensitive care based on trust and communication to protect the cultural, psychosocial and spiritual values of its patients. These included specific areas identified in this study, reflecting that patients had felt involved, informed and participant in their care, and the inclusion of isiXhosa speaking staff members in the interdisciplinary team, ensuring that language, culture and communication difficulties were not a barrier to palliative care access.

Thus it is demonstrated that individual context, the needs experienced by patients, the context in which GH provides palliative care and the provision of culturally sensitive care all relate to and influence each other.

6.6 Limitations

This study had a number of important limitations.

This study was only able to enroll 26 patients during the study period from September 1, 2006 to May 15, 2007 and this small cohort limited the generalizations that could be made. The problems of recruiting larger respondent numbers are recognised in palliative care research.¹⁰² It is postulated that enrolment was limited by patients being unfamiliar with research, some were very ill during the study period and patients with limited education and health care options may have felt vulnerable. These issues have been recognised by HPCA in their Research Ethics Committee: standard operating procedures.¹⁰³ The design and planning of future studies in Grahamstown should consider the potential problems associated with enrolling a larger cohort, the constraints of time and the costs of translations if the primary researcher is not isiXhosa speaking.

Despite every effort to be respectful and culturally sensitive, the researcher was a member of a different culture and language group. The researcher influences the process of the research project from developing a research question to conclusions and recommendations, and this process is not neutral. The researcher may have introduced her own cultural biases in developing the data collection tools, collecting data, analysis of the data and formulation the discussion, thus limiting conclusions that have been drawn. It was a fundamental limitation to this research project that it proposed to look at a specific language and culture group and that the researcher was not part of this group. There were also barriers in the interview process that related to issues raised above, as the researcher was not an isiXhosa speaker and the interviews were conducted by a research assistant. The presence of the researcher in the interviews may have negatively influenced the amount of information respondents were prepared to disclose. Patients in the group were also not familiar with research interviews and despite efforts to put patients at ease, some patients were clearly not relaxed during the interviews.

The design of the data collection tools did not identify patients who had children but did not support them. This particularly excluded data for men who had children but who were not involved financially in their care. The importance of fathers as resource in the face of HIV infection was noted in the literature review and the concerns of mothers' regarding the care of their children made this an important limitation.

The random selection of respondents to complete the SSI resulted in a demographic that did not have the same profile for dependent numbers as the SQ. Thus the very evident concerns expressed in the SQ of mothers who were worried about the long term care and financial support of their children were not evident in the SSI data. A future study to explore these issues could be undertaken to address these concerns.

This was a cross-sectional study and as data was collected once off, no conclusions could be drawn reflecting how needs changed over time. This related to needs across all domains and was also relevant as patient reported ranking of needs may have changed relating to life events and stage of disease.

For pragmatic purposes data collection in the spiritual domain was restricted by the inclusion of only the first three questions from the Spiritual Assessment Tool (FICA) and there was no in-depth exploration of spiritual needs. Conclusions regarding spiritual needs were further limited as no respondents identified spiritual issues in their self-ranking of problems or worries. This limitation could be explored in a study that focuses purely on the area of spiritual needs in HIV positive patients accessing palliative care at GH.

Study design did not allow for the effects on palliative care needs of ARV therapy and palliative care to be examined separately. Furthermore, the conclusions regarding met needs were based on respondent reports of how needs had been met as the study did not collect data at admission and re-administer the SQ or SSI to compare outcomes after palliative care interventions.

The data did not clearly describe how family needs had been met by GH despite the description of a number of family related issues. It was also not clear how GH addressed the issues related to OVCs and the concerns of mothers regarding the long-term care of their children should they die. Data collection in these areas appears to have been limited by the design of the data collection tools.

This study was undertaken with no control cohorts. A control group who are HIV positive but not accessing palliative care would have allowed for conclusions that separated the outcomes of meeting needs with medical and ARV interventions from outcomes of palliative care interventions.

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CHAPTER SEVEN

7. Conclusion and recommendations

7.1 Conclusion

The individual context of a cohort of isiXhosa speaking HIV infected patients accessing palliative care from Grahamstown Hospice was described. Household composition was influenced by the cultural dynamics of this group as households were bound by kinship and resources were shared. Caregivers were most often family members but not spouses, which suggested that fathers/male partners were not active participants in care-giving or households. These households represented an important resource for patients facing HIV infection and this contrasted strongly with limited financial resources and employment opportunity. It is clear that HIV positive patients in this town need both ARV access and social welfare assistance to avoid being caught in the cycle of poverty associated with HIV infection.

The respondents in the study accepted the cause of their disease to be the HI virus and did not consider an ultimate cause that was grounded within the cultural and traditional belief systems of the amaXhosa. It would appear that knowledge was an important mediator in this process.

Needs were experienced across the spectrum of the defined palliative care domains. Physical needs were generally well met by a combination of ARV access, medical care and palliative care in Grahamstown, but for most respondents symptoms persisted to some extent despite being able to access ARV therapy. Economic needs outranked all other needs and these were very difficult for GH to address directly, and these also influenced the experience of emotional needs as they caused a great deal of distress. Male respondents in the study appeared to be reticent to communicate some of their needs to female GH palliative care workers and this was an important barrier to care.

Distress resulted from unmet needs, but was also influenced by the difficulties respondents faced as a result of a chronic life-threatening disease that has no hope of cure and the losses experienced as part of coming to terms with being HIV positive. This distress itself resulted in patients experiencing more emotional needs.

HIV positive individuals living in Grahamstown need to be able to mobilize resources to manage their disease. Some of these are mobilized by respondents themselves and others are mobilized as a result of the care partnership respondents have with GH. The relationship between respondents and GH is important as individuals are able to access palliative care, and the relationship itself has therapeutic value as respondents felt supported and cared for.

Effective communication is imperative as it determines how well needs are expressed, information is shared, education is offered and support is shown. Respondents had expectations of care when they engaged with GH and with other health care providers and these appeared to have been met as respondents felt that they had been involved in decision making both in their interaction with GH and other health care providers in the town.

This study demonstrated that context does influence palliative care needs of HIV positive individuals as it described resources that are available to people facing the realities of living with HIV/AIDS. For this cohort individual context appears to be the direct reason why economic needs dominate the other palliative care domains. But context also resulted in the very powerful family and household resource patients were able to access. Grahamstown Hospice was a significant resource to address the needs experienced by HIV positive individuals living in Grahamstown, and GH's impact on respondents' lived experience of HIV/AIDS motivates for integrated palliative care to be seen as a human right.

7.2 Recommendations

It is recommended that the palliative care needs of HIV positive people in Grahamstown who are not accessing palliative care are identified as this would allow for comparisons to be made and would possibly isolate the benefits from ARV therapy from the benefits of palliative care interventions.

The SQ design collected data reflecting the past three days but the self ranking and SSI suggested that there were concerns that related to things that may happen in the future. As it was clear that anticipatory concerns were a cause for distress and should be addressed, these issues could be the focus of a future study to identify the prevalence of anticipatory concerns and their influence on the experience of distress.

As respondents demonstrated a need for palliative care despite accessing ARV therapy it is proposed that palliative care providers undertake research that considers their role in the face of increasing numbers of chronic stable patients who are on ARV therapy.

The study suggested a number of specific recommendations to Grahamstown Hospice. Firstly, it is clear that patients experience ongoing symptoms despite ARV access and the use of patient outcome assessment tools like APCA POS will be helpful to ensure that needs are effectively identified, assessed and managed. Secondly, two further specific research projects are proposed. GH should consider a) research to explore the finding of this study suggesting that male patients are not communicating their needs to female GH staff and b) research to address the social and emotional needs of single mothers and OVCs.

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CHAPTER NINE

9. Appendices

9.1 Appendix 1: Category of care

Category 1 patients are seen monthly by a care worker. These patients are healthy but still need support to meet a particular need.

Category 2 patients are seen weekly by the Hospice sister or a care worker. These patients are not bedridden but have a currently problem that requires intervention.

Category 3 patients are ill and bed-ridden. They are seen at least twice weekly by a professional member of the Hospice staff, doctor, sister or social worker. The professional person will decide on the frequency of the visits.

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9.2 Appendix 2: Patient information sheet

Patient information sheet

Dear patient

You have been asked (by the hospice social worker) to participate in a study at Grahamstown Hospice. The purpose of this study is to investigate the needs of Xhosa patients who come to Grahamstown hospice, and how these needs are met.

Your participation in this study is voluntary. You may refuse to participate, or withdraw your participation at any stage. If you refuse to participate, the care you receive from Grahamstown hospice will not be affected in any way.

You will be interviewed by a researcher and an interpreter/research assistant, in a private room.

The questions in the first section of the questionnaire are details like your age, level of education, whether you are employed and details of where you live. These details will come from your hospice file. The second part of the interview are yes/no and scale questions. There are no right or wrong answers. Some patients will be asked to participate in the third section where you will be asked about your disease, symptoms and concerns and worries, and answer in your own words. There are no right or wrong answers. You will be able to ask the research assistant or the researcher questions during the interview if you do not understand something.

The interview will take approximately twenty minutes for the structured interview. If you are asked to participate in the unstructured part of the interview, this will take approximately thirty minutes in addition to the structured interview. The information you give will be kept confidential. If any immediate needs are identified during the course of the interview, you will be asked to report these to your hospice sister/nurse at your next visit, or give consent for the

researcher to speak to a member of the hospice team about your needs. Your name will not appear on your questionnaire.

Results and recommendations of this study will be fed back to Grahamstown Hospice. If you wish you will also receive the results of this study.

Thank you.

Researcher: Dr Barbara Matthews

Contact number: 0832369395

UCT Research Ethics committee contact details

Faculty of Health Sciences

Research Ethics Committee

E52- 23 Old Main Building, Groote Schuur Hospital, Observatory ,7925

Tel: 27 21 4066492 Fax: 27 21 4066411

University of Cape Town

9.3 Appendix 3: Consent form

Consent form

Consent to participate in this study will be taken by a Xhosa speaking research assistant

I, consent to participate in a study to identify the needs of patients in the Grahamstown hospice service. I understand that my participation is voluntary and that I may withdraw at any stage. If I refuse to participate I understand that the care I receive will not be influenced in any way.

If any needs are identified during the course of the interview, I understand that I will be asked to report these to my hospice nurse/sister at my next visit OR I give the researcher permission to speak to a member of the hospice team about my problem so it can be addressed. (Please delete one)

I understand that all information I give will be kept confidential and I that I will not be identified on my questionnaire.

I understand that the overall results of this study will be communicated to the management of the Grahamstown hospice services.

I would like/would not like to receive results of the study

Name.....

Date.....

Witness.....

Date.....

Researcher's name: Dr Barbara Matthews Tel Number 0832369395

9.4 Appendix 4: Demographic data sheet

Demographic details

1	Age at last birthday	
2	Sex	
3	Marital status (Y/N)	
4	Number of dependents	
5	Level of education	
6	Employed – no	
	Employed – permanent	
	Employed - temporary	
7	Other income - no	
	Other income – grant	
	Other income – policy	
	Other income – please specify	
Details of HIV disease		
1	Is the patient on ARV's (Y/N)	
2	Starting date	
3	Was the patient referred to hospice by – hospital (Y/N)	
	Clinic (Y/N)	
	GP (Y/N)	
	Other – please specify	
Social/Residential context		
1	In which area (suburb) of Grahamstown does the patient live	
2	Does the patient live – in their own home	
	Rented home	
	Home of a family member	
	Home of a friend	
	Other – please specify	
3	Does the home have running water – in the house	
	In the yard	
	Other – please specify	
4	Does the patient have – a flush toilet	
	A pit toilet	
	Other – please specify	
5	How many people live with the patient	
6	Do they contribute to the household income	
7	What is this patient's diagnosis, CD4 count on admission	

9.5 Appendix 5: Structured questionnaire

Structured Questionnaire

A	<i>Hospice</i>	
i.	What name do you give hospice?	
ii.	Do you always see an isiXhosa speaking sister (Y/N)	
B	<i>Diagnosis</i>	
iii.	Why were you referred to hospice?	
1	Because you are HIV positive Y/N	
2	Because you have cancer Y/N	
3	You have another illness- please specify	
4	You don't know	
C	<i>Traditional healers</i>	
iv.	Have you seen a traditional healer since you diagnosis? (Y/N)	
D	<i>Physical symptoms</i>	
v.	Have you been affected by pain in the last three days?	
0	No, not at all	
1	Slightly, but not bothered by it	
2	Moderately, pain limits some activity	
3	Severely, activities markedly affected	
4	Overwhelmingly, unable to think of anything else	
vi.	Have you been affected by other symptoms in the last three days?	
0	No, not at all	
1	Slightly	
2	Moderately	
3	Severely	
4	Overwhelmingly	

E	<i>Social and family issues</i>	
vii	Is a member of your family looking after you? (Y/N)	
F	<i>Emotional symptoms</i>	
viii	Over the last three days have you been feeling anxious or worried about your illness?	
0	No	
1	Occasionally	
2	Sometimes	
3	Most of the time	
4	Yes, always	
G	<i>Spiritual issues</i>	
ix.	Do you have a faith?	
a	Yes	
b	No	
c	Not sure	
x.	What role does your faith, or your church, play in your illness?	
0	No role	
1	Insignificant role	
2	Important role	
3	Significant role	
4	Overwhelming role	
H	<i>Economic concerns</i>	
xi.	Are you worried about money matters?	
0	Not at all	
1	Slightly	
2	Moderately	
3	Severely	
4	Overwhelmingly, it is all I think about	
xii.	Are you worried about food / having enough food for the household?	
0	Not at all	

1	Slightly	
2	Moderately	
3	Severely	
4	Overwhelmingly, it is all I think about	
I	<i>Current concerns</i>	
xiii	What are the three biggest worries or problems you have today?	
J	<i>Care decisions</i>	
xiv.	Do you feel you have been involved in decisions regarding your care since your illness has been diagnosed?	
0	Yes, I have always felt fully involved	
1	Most of the time I have felt involved	
2	I have sometimes felt involved	
3	I have seldom felt involved	
4	No, I have never felt involved	

University of Cape Town

9.6 Appendix 6: POS (Patient Outcomes Scale)

Patient Outcome Scale **PATIENT QUESTIONNAIRE**



Patient name: Assessment date:

Date of birth: Assessment no:

Care setting:

Please answer the following questions by ticking the box next to the answer that is most true for you. Your answers will help us to keep improving your care and the care of others. Thank you.

- 1 Over the past 3 days, have you been affected by pain?
 0 Not at all, no effect
 1 Slightly – but not bothered to be rid of it
 2 Moderately – pain limits some activity
 3 Severely – activities or concentration markedly affected
 4 Overwhelmingly – unable to think of anything else
- 2 Over the past 3 days, have other symptoms e.g. feeling sick, having a cough or constipation been affecting how you feel?
 0 No, not at all
 1 Slightly
 2 Moderately
 3 Severely
 4 Overwhelmingly
- 3 Over the past 3 days, have you been feeling anxious or worried about your illness or treatment?
 0 No, not at all
 1 Occasionally
 2 Sometimes – affects my concentration now and then
 3 Most of the time – often affects my concentration
 4 Can't think of anything else - completely pre-occupied by worry and anxiety
- 4 Over the past 3 days, have any of your family or friends been anxious or worried about you?
 0 No, not at all
 1 Occasionally
 2 Sometimes – it seems to affect their concentration
 3 Most of the time
 4 Yes, always preoccupied with worry about me
- 5 Over the past 3 days, how much information have you and your family or friends been given?
 0 Full information – always feel free to ask what I want
 1 Information given but hard to understand
 2 Information given on request but would have liked more
 3 Very little given and some questions were avoided
 4 None at all

6 Over the past 3 days, have you been able to share how you are feeling with your family or friends?

- 0 Yes, as much as I wanted to
- 1 Most of the time
- 2 Sometimes
- 3 Occasionally
- 4 Not at all with anyone

7 Over the past 3 days, have you been feeling depressed?

- 0 No, not at all
- 1 Occasionally
- 2 Sometimes
- 3 Most of the time
- 4 Yes, definitely

If you have placed a tick in boxes 3 or 4 for this question, please speak with your nurse or doctor at your next appointment.

8 Over the past 3 days, have you felt good about yourself as a person?

- 0 Yes, all the time
- 1 Most of the time
- 2 Sometimes
- 3 Occasionally
- 4 No, not at all

9 Over the past 3 days, how much time do you feel has been wasted on appointments relating to your healthcare, e.g. waiting around for transport or repeating tests?

- 0 None at all
- 2 Up to half a day wasted
- 4 More than half a day wasted

10 Over the past 3 days, have any practical matters resulting from your illness, either financial or personal, been addressed?

- 0 Practical problems have been addressed and my affairs are as up to date as I would wish
- 2 Practical problems are in the process of being addressed
- 4 Practical problems exist which were not addressed
- 0 I have had no practical problems

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

- 1
- 2

12 How did you complete this questionnaire?

- 0 On my own
- 1 With the help of a friend or relative
- 2 With help from a member of staff

POS Version 2

(Kings College London. Questionnaires and tools. Palliative Outcomes Scale. [updated 2008 July 22; cited 2010, May30]. Available from: <http://www.kcl.ac.uk/schools/medicine/depts/palliative/gat/pos.html>)

9.7 Appendix 7: Spiritual Assessment Tool (FICA)

Spiritual Assessment Tool

An acronym that can be used to remember what is asked in a spiritual history is:

F: Faith or Beliefs
I: Importance and influence
C: Community
A: Address

Some specific questions you can use to discuss these issues are:

F: What is your faith or belief?
Do you consider yourself spiritual or religious?
What things do you believe in that give meaning to your life?

I: Is it important in your life?
What influence does it have on how you take care of yourself?
How have your beliefs influenced your behavior during this illness?
What role do your beliefs play in regaining your health?

C: Are you part of a spiritual or religious community?
Is this of support to you and how?
Is there a person or group of people you really love or who are really important to you?

A: How would you like me, your healthcare provider, to address these issues in your healthcare?

General recommendations when taking a spiritual history:

1. Consider spirituality as a potentially important component of every patient's physical well being and mental health.
2. Address spirituality at each complete physical examination and continue addressing it at follow-up visits if appropriate. In patient care, spirituality is an ongoing issue.
3. Respect a patient's privacy regarding spiritual beliefs; don't impose your beliefs on others.
4. Make referrals to chaplains, spiritual directors, or community resources as appropriate.
5. Be aware that your own spiritual beliefs will help you personally and will overflow in your encounters with those for whom you care to make the doctor-patient encounter a more humanistic one.

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9.8 Appendix 8: Semi-structured interview

Semi-structured questionnaire – interview guide

1. Tell me about your illness
2. When did you first come to hospice?
3. Why were you referred to hospice?
4. What does your illness mean to you
5. What name do you give hospice?
6. What does this name mean to you
7. Who has helped you during your illness?
Prompts: family, friends, community, church, hospital, hospital, clinic, traditional healer
8. How often have you consulted a traditional healer since you became ill
Prompt for interpreter: once a week, once a month, once every six months, once a year.
Have you consulted a traditional healer about your illness, or about some other personal or family matter?
9. What kind of help have you received from these people/ groups?
10. What other help do you need?
11. Do you have physical problems that are worrying you?
12. Have you discussed these with the hospice staff?
13. How have you been helped?
14. What other help do you need for your physical problems?
15. Are you worrying about family matters and concerns that you are having difficulty dealing with because your illness is interfering?
Prompt for interpreter:
Getting children settled in school
School fees/ uniforms
Grants
Being present at weddings
Being present at funerals
Circumcision rituals / umgidis
Ukubuyiso / ukukhapho rituals

16. Have you discussed these with the hospice staff?
17. How have you been helped?
18. What other help do you need for your family concerns?
19. How are you feeling today in your heart, soul, inside (non –physical, social, emotional or financial concerns)

Prompt: are you feeling?

Isolated

Sad/depressed

Anxious

Frightened

Are you able to sleep well?

Other

20. Have you discussed these with the hospice staff?
21. Do you feel you have helped?
22. What other help do you need for these problems?
23. Do you feel you have been involved in decisions regarding your care?
Prompt: Where do you feel you were not involved?
24. How do you feel you have been involved?

9.9 Appendix 9: Distress protocol

Distress protocol

Patients would be interviewed in a private room

Interview procedure would be explained before the interview commenced

Patients would be informed that they may ask for the interview to be terminated at any point

If patients showed any signs of distress – crying, restlessness, distraction, or any other body language that suggested distress – they would be asked if they would like to terminate the interview

If patients asked for their interview to be terminated they would be asked if they would like to see their hospice Sister or the Hospice social worker to discuss how they were feeling

The patients would be reassured by the researcher and escorted back to the waiting area only once they were feeling calm again

An appointment would be arranged by the researcher for the patient to see their Hospice Sister the next day and for the Hospice social worker to follow up with the patient

The researcher would contact both the sister and the social worker to confirm that the meetings had taken place

Patients who terminated their interview would be thanked for their participation and reassured of the ongoing support of Hospice

9.10 Appendix 10: Ethics approval



UNIVERSITY OF CAPE TOWN

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17 May 2006

REC REF: 181/2006

Dr B Matthews
Palliative Medicine

Dear Dr Matthews

PROJECT TITLE: THE PALLIATIVE CARE NEEDS OF STAGE III AND IV HIV/AIDS XHOSA SPEAKING PATIENTS IN THE GRAHAMSTOWN HOSPICE SERVICE, AND PHYSICAL, EMOTIONAL, SOCIAL/FAMILY, SPIRITUAL AND ECONOMIC FINDINGS IN RELATION TO THE GRAHAMSTOWN GEOGRAPHIC, SOCIAL AND ECONOMIC CONTEXT

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

It is a pleasure to inform you that the Ethics Committee has formally approved the above-mentioned study on the 12 May 2006.

Adherence to ethical standards remains the responsibility of the investigator and the supervisor.

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 E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

Please quote the REC. REF in all your correspondence.

lemjedi

Yours sincerely

DR. M. BLUCKMAN
CHAIRPERSON, HSF HUMAN ETHICS

16/1/2011

9.11 Appendix 11: GH ethics approval

GRAHAMSTOWN HOSPICE



There isn't enough darkness in the universe
to extinguish the light of one small candle.

P.O. Box 664, GRAHAMSTOWN 6140
TELEPHONE: +27 (0) 46 522 9661
FAX: +27 (0) 46 522 9675
E-MAIL: hospice_psm@telkomsa.net

Application to Conduct Research

Name: *Barbara Matthews*

Postal address: *P.O. Box 48 Alexandria 6185*

Physical address: *Sten Byge Farm, Alexandria*

Contact numbers: *046 6540006 6540006 (fax) 08323641395*

Research affiliation (e.g. Rhodes University): *University of Cape Town*

Title of research: *The palliative care needs of Stage III-IV HIV/AIDS
1156 language Xhosa speaking patients in the Grahamstown
Hospice Service and caregivers, including social/housing.*

* Purpose of research: *Support - economic findings in relation to the programme.*
* Why do you need? *To see Grahamstown hospice social + economic context*
Please describe in detail how you intend to carry out your research at Grahamstown Hospice

Please see methodology in attached proposal

How will informed client consent be attained? *Please attach example of consent form to this application.*

Please see attached proposal

What assurance of client confidentiality is in place?

*A hospice care worker will maintain + be trusted on confidentiality.
All records will be kept with the doctor + all names will not
be recorded*

Are there any other ethical considerations which have been considered?

*If any need are identified, the pt will be requested to
communicate them to the hospice staff. Please see consent form*

Please describe the process of verbal and written feedback which will be provided:

*Findings will be communicated to hospice +
recommendations will be made in writing once
research is complete*

GRAHAMSTOWN HOSPICE



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TEL: PHONE +27 10 45 622 9661
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E-MAIL: hospice_pgm@fukomsa.net

I, Suzanne Matthews undertake to -

- closely follow the research proposal that I have detailed above.
- ensure that informed consent is obtained from all Hospice research participants.
- ensure the rights, including confidentiality, of all Hospice clients are upheld at all times.
- maintain contact with the Hospice Research Coordinator in the course of the research.
- provide verbal feedback to the relevant Hospice staff.
- submit a final report of my research process and findings to the Hospice upon completion of the research project.

Signature

11.04.06

Date

For Official use only

Staff input in response to research proposal

STAFF WILL BE OF GREAT VALUE TO HOSPICE RE. EVALUATING
OUR PROVISION OF HOLISTIC CARE & FACTORS AFFECTING CARE

Research approval? YES

Additional conditions required

NO

Grahamstown
Hospice Services

Research Coordinator

26/4/06
Date

Director

9.12 Appendix 12: Settlers Hospital ethics approval



PROVINCE OF THE EASTERN CAPE
ISEBE LEZENPILO - DEPARTMENT OF HEALTH - DEPARTEMENT VAN GESONDHEID
SETTLERS HOSPITAL
Private Bag X1007, **GRAHAMSTOWN**, 6140, SOUTH AFRICA

Ref No:

Telephone: 046 - 622 2215

Enquiries: Mrs Solomon

Facsimile: 046 - 622 5366

Date: 8 September 2006

Dr B. M. Ullrich
GLEN DYE
P.O. Box 48
ALEXANDRIA
6185

Dear Doctor

RE: PALLIATIVE CARE RESEARCH

I hereby authorise you to conduct research on Palliative Care, at Settlers Hospital, Grahamstown.

I believe that it will benefit our patients and the community at large, and strengthen the partnership between the Hospital and Grahamstown HOSPICE.

Yours faithfully

IRENE SOLOMON
ACTING CEO CLUSTER: MAKANA

9.13 Appendix 13: Approval to access ARV rollout details from Settlers Hospital ARV Clinic (Masonwabe)



PROVINCE OF THE EASTERN CAPE
ISEBE LEZEMPILO - DEPARTMENT OF HEALTH - DEPARTEMENT VAN GESONDHEID
SETTLERS HOSPITAL
Private Bag X1007, **GRAHAMSTOWN**, 6140, SOUTH AFRICA

Ref No: Telephone: 046 - 522 2215
Enquiries: Mrs I Solomon Facsimile: 046 - 522 5366
Date: 21 May 2007

DR B MATTHEWS
P.O. BOX 48
ALEXANDRIA
6185

Dear Dr Matthews

RE: RESEARCH PROJECT M PHIL

I hereby give permission to you to access the statistics of the A.R.V program. I believe that it will ultimately be beneficial to the patients we serve.

I wish you all the best with your research.

Yours faithfully

MRS SOLOMON
ACTING EXECUTIVE OFFICER
/bbg